INTERNATIONAL FEDERATION
FOR SPINA BIFIDA
AND HYDROCEPHALUS

2024 ANNUAL REPORT

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FOREWORD

The International Federation for Spina Bifida and Hydrocephalus (IF) is honoured to collaborate with our dedicated members and partners worldwide, all focused on improving the lives of individuals with Spina Bifida and Hydrocephalus (SBH) and their families. In light of the challenges faced by our SBH community, it is essential to optimise the use of our limited resources.

The 2024 Annual Report highlights significant achievements in advancing human rights, primary prevention, optimising care, raising awareness, and fostering international solidarity. A major milestone was the 30th International Conference on Spina Bifida and Hydrocephalus in Kuala Lumpur, Malaysia, which focused on bridging gaps in healthcare and prevention through a community-centred, multidisciplinary approach. The conference encouraged meaningful interactions among healthcare professionals, researchers, individuals with SBH, families, and scholars. It featured a range of sessions on topics such as mobility, psychological health, advocacy, and wellness, with a special focus on local SBH associations and their initiatives. The collective impact of the SBH community continues to inspire us!

Additional achievements in 2024 include engaging our community through informative webinars on international awareness-raising days such as the World Folic Acid Awareness Week (WFAAW24) and a webinar on mental health. The IF statements on 'Technologies and Accessibility in Education' and 'Mental Health in Focus', along with several consultations and scientific publications, reinforced our position on critical issues. To strengthen global ties, the twinning between the EU and Ukraine expanded our collaborative network. Additionally, we partnered on events like the World Birth Defect Day (WBDD) webinar, the WHA77 side event, and a youth meeting that united five youth groups from across borders.

IF is profoundly grateful for the unwavering support and active participation of our members and partners. We sincerely thank everyone who has contributed to our work, including the chairs, standing committee members, and our volunteers.

Reflecting on the many opportunities and initiatives of the past year, we are excited to make 2025 another year of progress alongside you!

Victoria Sandoval*, IF President*
Dr. Sylvia Roozen*, IF Secretary General*

LIST OF ABBREVIATIONS

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

ABOUT IF

WHO WE ARE

The International Federation for Spina Bifida and Hydrocephalus or IF 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 (NTDs) 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

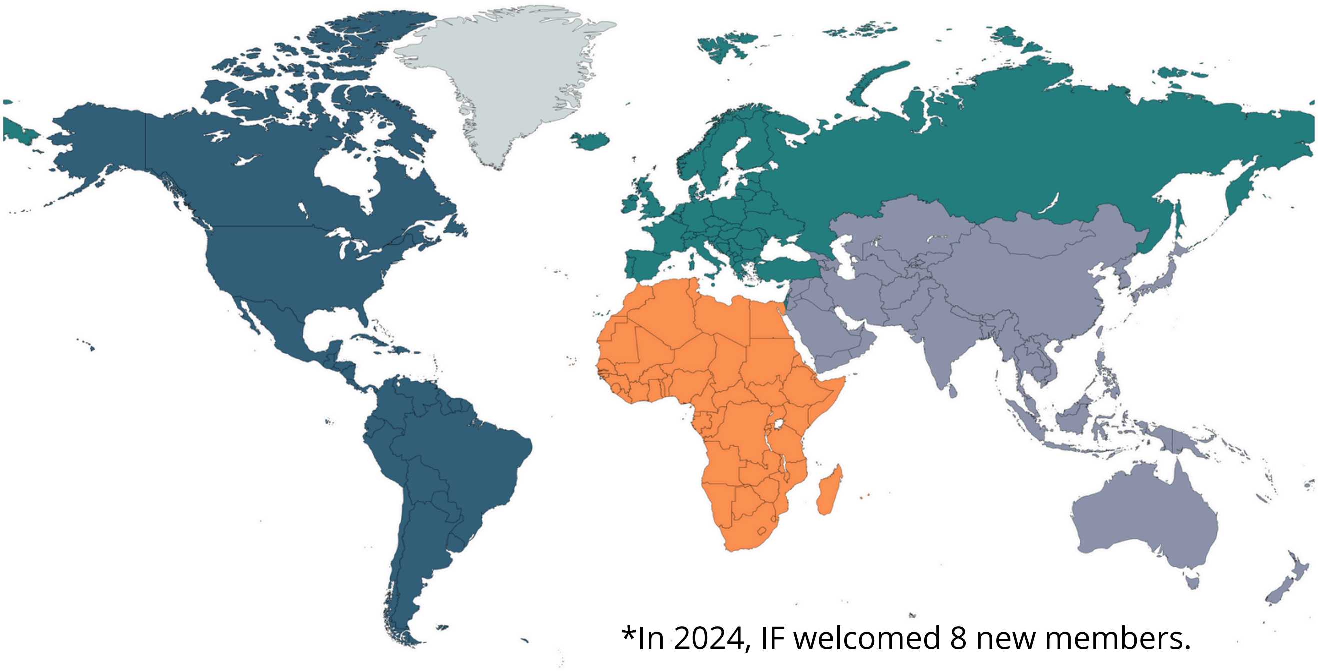
Human Rights: The promotion and protection of the human rights of people with SBH in accordance with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is our highest value.

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



*In 2024, IF welcomed 8 new members.

The Americas

Argentina - Asociación para Espina Bífida e Hidrocefalia (APEBI)
Brazil - Associação Brasileira de Espinha Bifida (ABRASSE)*
Canada - Individual representation
Canada - Spina-bifida 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 Bifida and Related Disabilities (HASBRD)*
Honduras - Fundación Amado Josué
México - Asociación Mexicana De Espina Bifida A.C. (AMEB)
Panama - Fundacion Zero Limite Espina Bifida Panamá*
Perú - Asociación de Espina Bífida e Hidrocefalia del Perú (ASESBIH)
USA - Hydrocephalus Association
USA - Spina Bifida Association of America (SBAA)

Africa

Algeria - Association des Parents et Malades Spina Bifida Béjaïa
Congo - Appui au Développement de l'Enfant en Détresse (ADED)*
Egypt - Waad Spina Bifida Foundation
Ethiopia - HOPE-SBH
Gambia - Lamin Keita's Hope*
Ghana - Spina Bifida & Hydrocephalus Foundation-Ghana
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 - 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

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 (VSH)
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 - Rygmarvsbroksforeningen af 1988
Estonia - MTÜ Eesti Seljaajusonga ja Vesipeahaigete Selts
Finland - Suomen CP-liitto ry
France - Association Nationale Spina Bifida et Handicaps Associés (ASBH)
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 hidrocefālijas 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 Bífida e Hidrocefalia de Portugal (ASBIHP)
Romania - Asociatia Romana de Spina Bífida 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 spoločnost' pre spina bifida a/alebo hydrocefalus, o.z.
Spain - Associació Catalana d'Espina Bífida i Hidrocefàlia (ACAEBH)
Spain Madrid - Espina Bífida e Hidrocefalia Madrid - AMEB
Spain Murcia - Asociación Murciana de Padres con Hijos conde Espina Bífida
Spain - Federación Española de Asociaciones de Espina Bífida 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
Turkiye - Türkiye Spina Bifida Derneği
UK - Shine Charity
UK - Harry's Hat
Ukraine - Parents Association for Spina Bifida and Hydrocephalus 'Lights of Spirit'

Asia-Pacific

Australia - Spina Bifida Hydrocephalus Queensland
Australia - Individual representations
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
Malaysia - Spina Bifida Association Malaysia (SIBIAM)
Mongolia - Mongolian Spina Bifida Foundation 'Maral Angel'
Pakistan - Individual representation
Pakistan - Pakistan Federation For Spina Bifida and Hydrocephalus
Panama - Fundación Zero Limite Espina Bifida Panamá
Philippines - Spina Bifida Support Group Foundation, Inc*
South Korea - Korea Spina Bifida Patient Association (KPSPA)
Taiwan - Taiwan Spinal Bifida Support Society

BOARD OF DIRECTORS

Victoria Sandoval
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Bulgaria

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Spain

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Italy

Sonia Uribe*
Colombia

Rasmus Isaksson*
Sweden

Dr. František Horn*
Slovakia

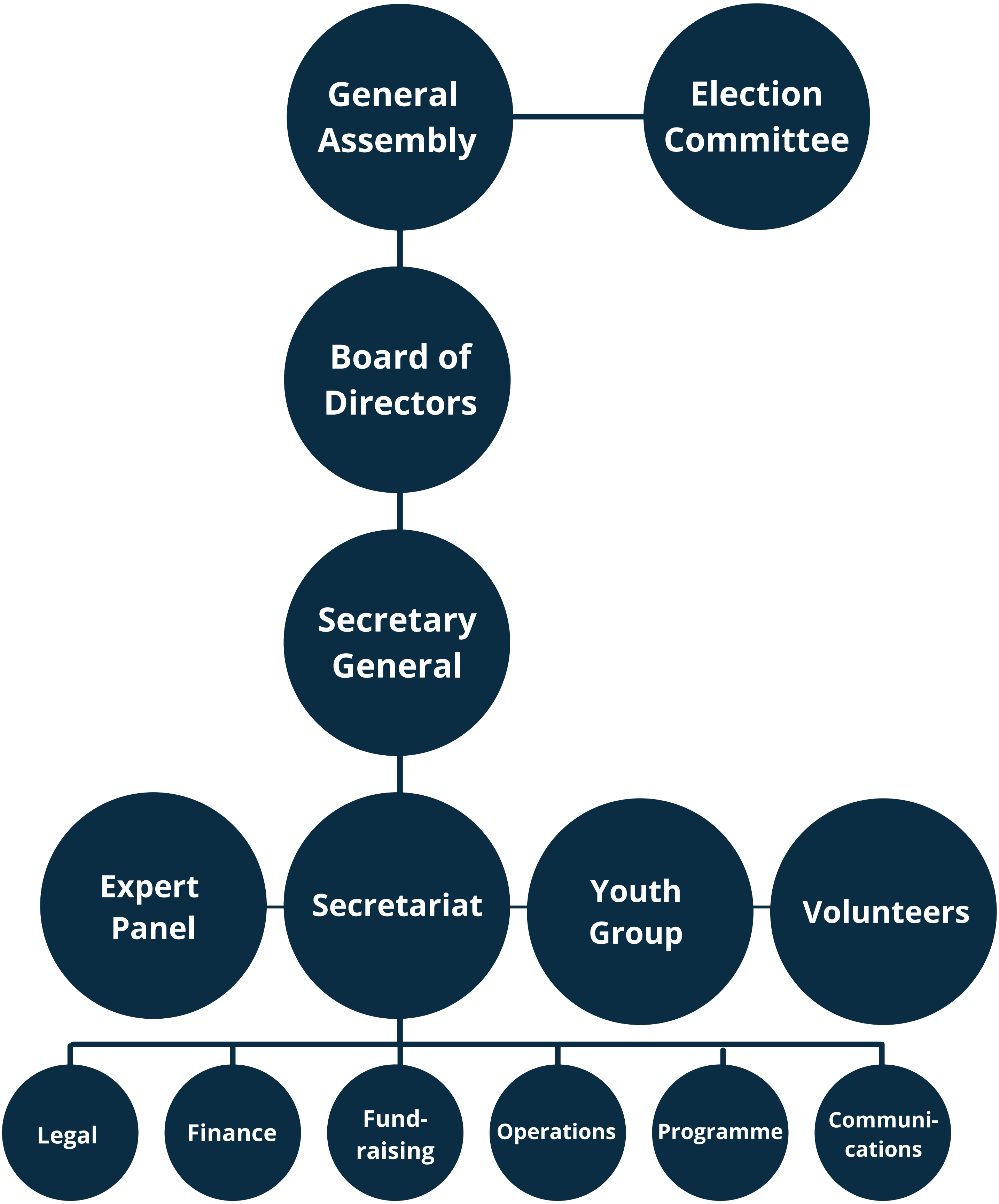
SECRETARY GENERAL

Dr. Sylvia Roozen

In 2024, we welcomed two new board members, Slaveya Kostadinova and Dr. Santosh Karmarkar.

** We said goodbye to the outgoing IF president Cato Lie and board members Emma Suardiaz, Papatya Alkan Genca, Giulia Bizzotto, Rasmus Isaksson, František Horn, and Sonia Uribe.*

IF ORGANOGRAM



ELECTION COMMITTEE

In 2024, the General Assembly elected the following members for the election committee:

- Terezia Drdul - Slovenská spoločnosť' pre Spina Bifida a/ alebo Hydrocefalus, o. z.
- Dr. Margo Whiteford - Spina Bifida Hydrocephalus Scotland (SBHS)
- Hassan Funmilayo - Spina Bifida and Hydrocephalus Association of Nigeria (SBHAN)

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 SBH and/or specialists in the field of disability in general. In particular, the scientific conference committees for IF conferences support the wider scientific deepening of our federation.

IF International Youth Group SBH

In 2024 the IF International Youth Group SBH consisted of the following members: Kateryna Shcherbyna (Chair; Parents Association for Spina Bifida and Hydrocephalus 'Lights of Spirit' Ukraine), Laura Rosillo Beneyto (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'), 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), Jurn Anthonis (Vlaamse Vereniging voor Spina Bifida en Hydrocephalus vzw Belgium), Chen Miaohua (Taiwan Spina Bifida Support Association), and Harichandana Mynampati (Spina Bifida Foundation India).

MAIN ACHIEVEMENTS

Quarter

January - March

Community Building

Through member meetings and regional members meetings

Advocacy

Through the WFAAW webinar ‘Let’s Thrive Impact!’ and share the importance of the implementation of the WHA76.19 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 (WFAAW), Rare Disease Day (RDD), World Birth Defects Day (WBDD), International Women's Day (IWD)

Twinning Opportunities

Through the EU-Ukraine Webinar Series

Quarter 2

April - June

Advocacy

Through the WHA77 Side Event Congenital Anomalies and Universal Health: Leaving No One Behind during the United Nations High Level Meeting on Universal Health Coverage

Awareness Raising

Through an international awareness campaign: IF Siblings Day, Global Day of Parents

Twinning Opportunities

Through the 'Meet and Greet' meeting as part of the webinar series on Mental Health & Urological Management

Community Building

Through regional members meetings & the IF spring webinar

Publications

Of the IF Annual Report, Membership Guide, Consultation EU4Health 2025 Work Programme via EDF, IF statement on Technologies and Accessibility in Education and toolkits

Quarter 3

July - September

Awareness Raising

Through the international awareness days: the International Youth Day (IYD) and youth webinar 'Mental Health Matters'

Community Building

Through regional members meetings and IF members communications coordinators meetings

Partnership Strengthening

Through communications and collaborations with DG EMPL, and participation in the European Commission Disability Platform to joint advocacy with EU institutions and meeting with FFI to advance Large Scale Food Fortification (LSFF)

Advisory Groups

Kick off meeting of the IF Genetics Advisory Group

Quarter 4

October - December

International Solidarity

Through the World Spina Bifida and Hydrocephalus Day (WSBHD), as well as the 30th International Conference on Spina Bifida and Hydrocephalus

Community Building

Through the Euregional Youth Meeting on the International Day for Persons with Disabilities (IDPD) with 5 youth groups from Belgium, the Netherlands, France, Poland and IF International Youth Group SBH

Awareness Raising

Through international awareness days: International Day for Older Persons, World Mental Health Day (WMHD), International and European Days for Persons with Disabilities (EDPD)

Twinning

Through the EU-Ukraine Webinar Series

Training Opportunities

Through IF members training 'Youth Advocacy'

Publications

The IF Statement on Mental Health in Focus and the Kuala Lumpur Declaration

HUMAN RIGHTS

The year 2024 marked a major advancement in two of IF's high-priority advocacy topics: (1) bridging healthcare and prevention gaps and (2) improving a multidisciplinary care approach. These advocacy priorities emerged throughout the year in all IF's policy activities, especially in the Kuala Lumpur Declaration, which calls for global action to adopt a human rights-based approach to the prevention of NTDs and to ensure a multidisciplinary care approach for individuals living with SBH. Moreover, through its statements and other important scientific publications, participation in consultations with partners, and collaboration with international partners and organisations, IF has addressed important topics for the SBH community.

THE KUALA LUMPUR DECLARATION

The 30th International Conference on Spina Bifida and Hydrocephalus, held in Kuala Lumpur from October 24th to 26th, culminated in a historic declaration urging global action to improve the prevention of NTDs and ensure continuous, coordinated, and inclusive multidisciplinary care for individuals affected by SBH throughout their lives, from childhood to adulthood. The event brought together experts, researchers, healthcare professionals, and members of the SBH community and their families to discuss solutions to break down barriers and improve quality of life.

The 30th
International Conference On
Spina Bifida & Hydrocephalus

Organised by:

Supported by:

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

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

Kuala Lumpur Declaration

Preamble

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

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

Declaration

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

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

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)[6] recognizes in Article 25 that persons with disabilities have the right to the highest attainable standard of health without discrimination. Prevention and access to multidisciplinary care for individuals with SBH are fundamental

Organised by the Spina Bifida & Hydrocephalus Association of Malaysia (SIBIAM) and IF, the conference facilitated discussions and collaboration, leading to a call for all relevant stakeholders to support and implement the commitments outlined in the declaration as follow:

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

POLICY STATEMENTS

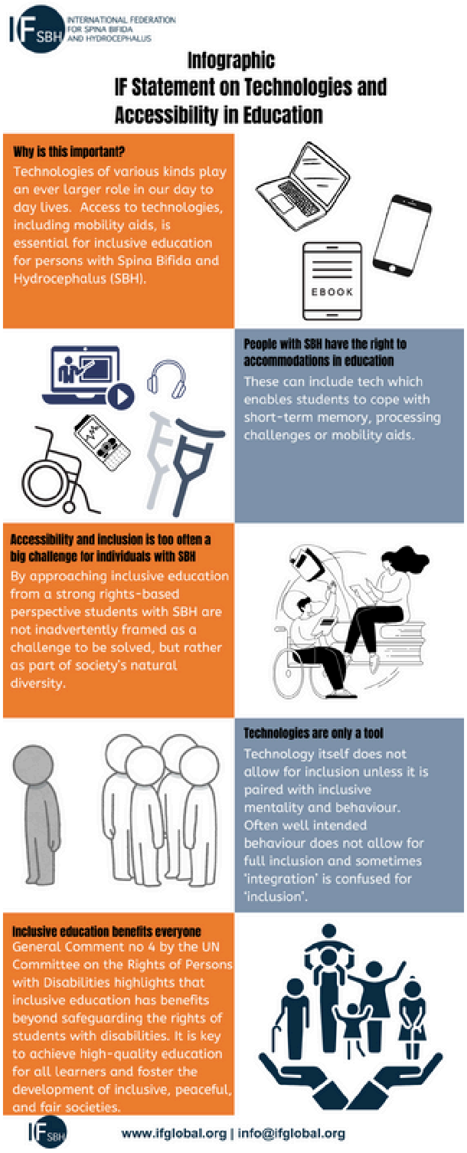
In addition to the Kuala Lumpur Declaration, IF published two more policy statements addressing important topics based on the input by members.

IF Statement on Technologies and Accessibility in Education

Technology plays a crucial role in improving mobility and accessibility for people with disabilities, including the global SBH community. As society becomes more reliant on technology, particularly in education, it is important to prioritise accessibility and inclusive education, especially during the transition from childhood to adulthood. Assistive technologies and mobility aids are essential in achieving these goals. The IF community emphasises that the voices of those directly affected by these changes must be heard before new technologies are implemented, particularly in schools. The IF Statement on Technologies and Accessibility in Education stresses the importance of implementing reforms with an inclusive mindset to ensure the rights of persons with disabilities are respected.

In this statement, attention was given to the following:

- Technologies can improve accessibility and inclusion for people living with disabilities, but they can also create barriers. For this reason, a human rights-based approach is needed to ensure that technological advancements truly contribute to inclusive education for people with SBH;
- Inclusive education is a human right established by the the UNCRPD and inclusion in school should not be seen as passive integration but as a systemic reform to ensure equal opportunities for all students;
- Governments and institutions must guarantee the right to inclusive education by providing appropriate accommodations, including assistive technologies and mobility aids and ensuring that technologies promote inclusion;
- The cost of assistive technologies is a significant barrier, especially for children with disabilities who require frequent updates. Lack of proper training for school staff and low awareness of disability rights hinder inclusion;
- The recommendations in this field are to encourage greater investments to ensure that all students with disabilities have access to the necessary study tools, promote awareness campaigns, enhance the training of school staff, and improve the accessibility of school environments, preventing technology from replacing the necessary structural modifications.



Infographic
IF Statement on Technologies and Accessibility in Education

Why is this important?
Technologies of various kinds play an ever larger role in our day to day lives. Access to technologies, including mobility aids, is essential for inclusive education for persons with Spina Bifida and Hydrocephalus (SBH).

People with SBH have the right to accommodations in education
These can include tech which enables students to cope with short-term memory, processing challenges or mobility aids.

Accessibility and inclusion is too often a big challenge for individuals with SBH
By approaching inclusive education from a strong rights-based perspective students with SBH are not inadvertently framed as a challenge to be solved, but rather as part of society's natural diversity.

Technologies are only a tool
Technology itself does not allow for inclusion unless it is paired with inclusive mentality and behaviour. Often well intended behaviour does not allow for full inclusion and sometimes 'integration' is confused for 'inclusion'.

Inclusive education benefits everyone
General Comment no 4 by the UN Committee on the Rights of Persons with Disabilities highlights that inclusive education has benefits beyond safeguarding the rights of students with disabilities. It is key to achieve high-quality education for all learners and foster the development of inclusive, peaceful, and fair societies.

www.ifglobal.org | info@ifglobal.org

IF Statement on Mental Health in Focus

Mental health is essential for overall well-being, allowing individuals to handle challenges, reach their potential, and contribute to their communities. However, individuals with SBH face significant obstacles to mental well-being due to societal stigma, discrimination, and a lack of support systems.

With the support of the IF Youth Group SBH and the IF Working Group on Ageing with SBH, the IF Statement Mental Health in Focus was published. To create an inclusive world, IF calls on policymakers, healthcare professionals, and other stakeholders:

- To ensure the availability, accessibility, and variety of mental health services so that all individuals with SBH have access to inclusive psychological support services;
- To formulate, update, and enforce national policies, programs, and legislation on mental health, including codes of conduct to monitor the protection of human rights, in alignment with the UNCRPD;
- To provide and finance specialised training programs for healthcare professionals to effectively address the specific mental health needs of individuals with disabilities;
- To promote awareness of mental health through campaigns aimed at combating stigma related to disability and mental health;
- To safeguard and promote, at multiple levels, the inclusion and active involvement of the SBH community, organisations of persons with disabilities, and users and ex-users of mental health services. Provide leadership programs and skill development opportunities to enable SBH community members to actively influence social and political decisions, in adherence to the United Nation (UN) principle “Nothing About Us Without Us”;
- To integrate mental health into routine health information systems by collecting, analysing, and reporting disaggregated data.

IF SBH INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

IF Statement on Technologies and Accessibility in Education

The fast advancement of technologies of various kinds, and our increased reliance on them in everyday life, in education, employment and public life has led to improved accessibility and inclusion for many persons with disabilities. Consequently, there is also increased interest in using various forms of technology to achieve inclusive education. However, progress is never a linear benevolent process, and technologies can also be a contributing factor to inaccessibility and exclusion. Therefore, in this statement, IF outlines the bases and need for a human rights approach to this increasingly important topic and what needs to be done to ensure that technological progress contributes to attaining inclusive education for persons with Spina Bifida and/or Hydrocephalus (SBH).

Human rights

‘Leaving No One Behind’ is the core principle of the 2030 Agenda of the Sustainable Development Goals (SDGs). When discussing inclusion and persons with disabilities one must begin with the UN Convention on the Rights of Persons with Disabilities (UNCRPD). The general principles of the convention are outlined in article 3; they include but are not limited to respect for individual autonomy, non-discrimination, full and effective participation and inclusion in society, equality of opportunity as well as respect for differences of persons with disabilities as part of human diversity and humanity. These principles must be at the heart of anything and everything that

IF SBH INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

IF Statement on Mental Health in Focus

As declared by WHO, mental health is a state of mental well-being that allows people to cope with life’s challenges, realise their abilities, learn and work effectively and contribute to their community. Mental health has both intrinsic and instrumental value and is essential for our overall well-being. At any given time, a series of individual, family, community and structural factors can combine to protect or compromise mental health and people exposed to adverse conditions, such as poverty, violence, inequalities or disabilities, are at greater risk of developing mental health conditions, which frequently entail stigma, discrimination and human rights violations. Mental health conditions include mental disorders, psychological disabilities, and other mental states associated with significant distress, impaired functioning or risk of self-harm. Therefore, these conditions can lead to challenges in all aspects of life, including relationships with families, friends, and the community[1]. For this reason, it is important to put mental health in focus.

The International Federation for Spina Bifida and Hydrocephalus (IF) recognises mental health as a fundamental right for all, including those living with disabilities such as spina bifida and/or hydrocephalus (SBH). The SBH community, at every stage of life, often faces not only physical

INTERNATIONAL ORGANISATIONS AND PARTNERS

Building strong relationships with international organisations is a key aspect of IF's advocacy for the rights and needs of the SBH community, as exemplified by collaborative policy actions together with the European Commission Disability Platform and the World Health Organization (WHO).

The World Health Organisation

Following the adoption of the WHA Resolutions on the acceleration of efforts to prevent micronutrient deficiencies and their consequences, including spina bifida and other NTDs, through safe and effective food fortification in 2023, IF strengthened its partnership with the WHO. In 2024, IF became a member of the newly established WHO Civil Society Committee. Additionally, IF collaborated with WHO and other civil society partners to organize an in-person WHA side event titled ‘Congenital Anomalies and Universal Health: Leaving No One Behind’. In partnership with the WHO Regional Office for the Eastern Mediterranean (WHO EMRO), IF also conducted a study to provide a situational analysis of the impact of mandatory food fortification on NTDs in the EMR, assessing progress and identifying areas for improvement. Additionally, IF contributes to WHO's work by providing input during consultation processes on for instance newborn screening, diagnosis, and management of birth defects.

European Commission Disability Platform

IF has been a member of the Disability Platform since its inception and remained an active participant throughout 2024. The organisation advocated on key issues within the EU, contributed to the development of the annual work program, and participated in various meetings. In 2024, the priorities of the platform included the European Disability Card and the European Parking Card. Initiatives that ensure persons with disabilities can better realise their right to free movement within the EU.

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.

CONSULTATIONS & SCIENTIFIC PUBLICATIONS

IF also continued to advocate on key issues within the EU and the UN by contributing to public consultations. Participating in public and stakeholder consultations provides a valuable opportunity to raise awareness about the rights and needs of the SBH community within international organisations. Some of the consultations that IF participated in during 2024 include:

- IF response as part of the WHO consultation ‘Framework for integration of newborn screening, diagnosis and management of birth defects into routine health services in LMICs’;
- IF response to the consultation on the EU4Health 2025 Work Programme;
- IF provided input for the EDF Resolution on Disability Rights, Peace and Conflict;
- IF participated in an IDA consultation and gave input to the Global Disability Inclusion Report;
- IF provided input to the IDA consultation aimed to inform OPDs about funding mechanisms;
- IF response to the IDA ‘Call to Action on the Summit of the Future: Don’t leave youth with disabilities behind!’ by creating a 10-point action plan for disability inclusive development;
- IF, as a member of the Global Fortification Technical Advisory Group, contributed to the document ‘Include Large Scale Food Fortification in N4G Paris 2025, a Commitment Guide for the Paris Nutrition for Growth Summit’.

IF also strengthened its collaboration with healthcare professionals and academia through scientific publications. Notable examples include contributing to scientific articles such as:

- The 30th International Conference on Spina Bifida and Hydrocephalus Programme Book;
- Mosiello, G., Nijman, R., Radmayr, C., Dellenmark-Blom, M., Roozen, S., Jouannic, J. M., Stein, R. & Abrahamsson, K. (2024). Expertise Area 1.4: Nonsyndromic urogenital tract malformation (neurogenic bladder and spina bifida). In Rare and Complex Urology (pp. 107-128). Academic Press;
- Neural Tube Defects, ERN-ITHACA APOGeE Textbook.

AWARENESS RAISING

INTERNATIONAL AWARENESS DAYS

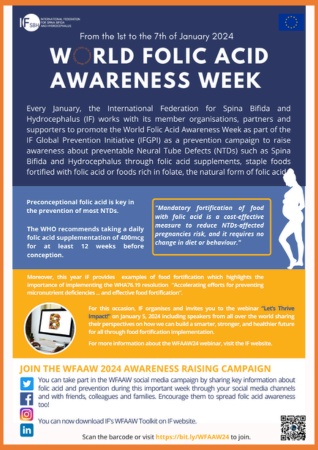
All of IF's activities are centered on advancing and protecting the rights of individuals with SBH. In 2024, IF organised a variety of initiatives to raise awareness about the rights of persons with SBH. These efforts included participating in meetings and events, contributing to consultations, and publishing statements. Awareness days, both European and international, were also crucial for IF in raising awareness about SBH through multimedia channels. These days provided opportunities for collaboration with IF members and partners, both in the EU and globally. By promoting these international, national, and European activities, IF worked to enhance visibility alongside its members and partners.

The overall objectives to raise awareness included:

- Promoting, protecting and monitoring the rights of persons with SBH;
- Ensuring that the perspective and needs of individuals with SBH and their families are represented in policy making;
- Supporting the implementation of the ESRPD and the European Pillar of Social Rights (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 SBH.

In 2024, IF continued to raise awareness about the rights of individuals with SBH and the UNCRPD among policymakers, stakeholders, and international organisations. IF organised awareness campaigns for several global events, including World Folic Acid Awareness Week (WFAAW), Rare Disease Day (RDD), World Birth Defects Day (WBDD), IF's Siblings Day, Global Day of Parents, International Youth Day (IYD), International Day of Older Persons (IDOP), World Spina Bifida and Hydrocephalus Day (WSBHD), and the International/European Day of Persons with Disabilities (IDPD/EDPD). 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
- International/European Days of Persons with Disabilities



From the 1st to the 7th of January 2024

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) 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.

Preconceptional 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 NTDs-affected pregnancies risk, and it requires no change in diet or behaviour."

Moreover, this year IF provides examples of food fortification which highlights the importance of implementing the WHA76.19 resolution "Accelerating efforts for preventing micronutrient deficiencies ... and effective food fortification".

For this occasion, IF organises and invites you to the webinar "Let's Thrive Impact!" on January 5, 2024 including speakers from all over the world sharing their perspectives on how we can build a smarter, stronger, and healthier future for all through food fortification implementation.

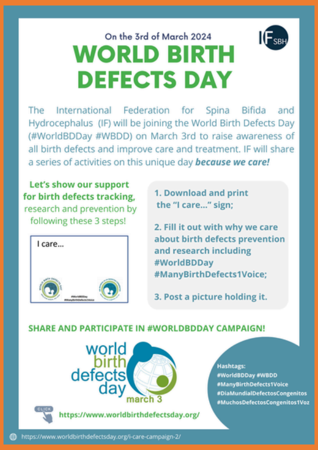
For more information about the WFAAW24 webinar, visit the IF website.

JOIN THE WFAAW 2024 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.

Scan the barcode or visit https://bit.ly/WFAAW24 to join.



On the 3rd of March 2024

WORLD BIRTH DEFECTS DAY

The International Federation for Spina Bifida and Hydrocephalus (IF) will be joining the World Birth Defects Day (#WorldBDDay #WBDD) on March 3rd to raise awareness of all birth defects and improve care and treatment. IF will share a series of activities on this unique day ***because we care!***

Let's show our support for birth defects tracking, research and prevention by following these 3 steps!

I care...

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 IN #WORLDBDDAY CAMPAIGN!

world birth defects day march 3

Hashtags:
#WorldBDDay #WBDD
#ManyBirthDefects1Voice
#DiaMundialDefectosCongenitos
#MuchosDefectosCongenitos1Voz

CLICK https://www.worldbirthdefectsday.org/

https://www.worldbirthdefectsday.org/i-care-campaign-2/

On the 10th of April 2024

IF'S SIBLINGS DAY

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

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

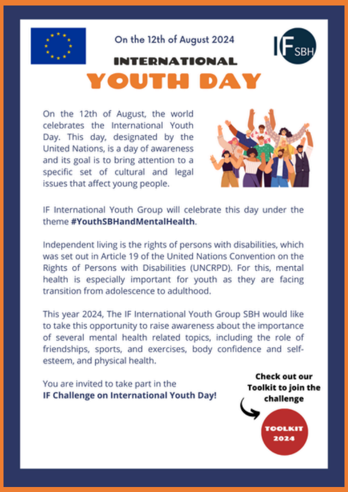
Share your picture as well as IF's **toolkit** on social media and tag us on Twitter, LinkedIn and Instagram @ifsbh and use the following hashtags #IFSiblingsDay #SBHSiblings #SmileSiblings.

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

IF has chosen the Smile logo and hashtag because:

"Siblings are lifelong best friends making each other smile every single day"

IF looks forward to receiving your pictures and sharing them!



On the 12th of August 2024

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 **#YouthSBHandMentalHealth**.

Independent 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). For this, mental health is especially important for youth as they are facing transition from adolescence to adulthood.

This year 2024, The IF International Youth Group SBH would like to take this opportunity to raise awareness about the importance of several mental health related topics, including the role of friendships, sports, and exercises, body confidence and self-esteem, and physical health.

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

Check out our Toolkit to join the challenge

TOOLKIT 2024

On the 1st of October 2024

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 that day, the International Federation for Spina Bifida and Hydrocephalus (IF) 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 2024

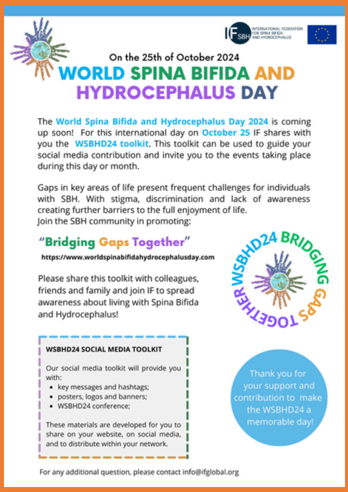
Our social media toolkit will provide you with:
- background information on this day;
- posters, logos and banners;
- key messages and hashtags;
- key links;
- a challenge to take part in;

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.

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

For any additional question, please contact info@ifglobal.org



On the 25th of October 2024

WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY

The World Spina Bifida and Hydrocephalus Day 2024 is coming up soon! For this international day on October 25 IF shares with you the WSBHD24 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.

Gaps in key areas of life present frequent challenges for individuals with SBH. With stigma, discrimination and lack of awareness creating further barriers to the full enjoyment of life.
Join the SBH community in promoting:

"Bridging Gaps Together"

https://www.worldspinabifidahydrocephalusday.com

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

WSBHD24 SOCIAL MEDIA TOOLKIT

Our social media toolkit will provide you with:
- key messages and hashtags;
- posters, logos and banners;
- WSBHD24 conference;

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

Thank you for your support and contribution to make the WSBHD24 a memorable day!

For any additional question, please contact info@ifglobal.org

EUROPEAN DAY OF PERSONS WITH DISABILITIES

November & December 2024

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 28 - 29.**

The focus of the 2024 agenda will be on:

① In-depth forward looking discussion on the **strategic objectives, policy proposals, and initiatives** for the next five years.

② Topics related to all **8 priority areas of the Strategy for the rights of persons with disabilities,** such as employment, independent living and transport, to name just a few.

③ **Raise awareness and tackle everyday challenges** faced by persons with disabilities.

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

World Folic Acid Awareness Week

Every January, IF works with its member organisations, partners, and supporters, to promote the WFAAW as part of the IF Global Prevention Initiative. The aims of the IFGPI are to raise awareness about preventable NTDs such as SB through folic acid supplements, staple foods fortified with folic acid, or foods rich in folate, the natural form of folic acid.

WORLD
FOLIC ACID
AWARENESS WEEK

Webinar
January 5th 2024

World Folic Acid Awareness Week 2024

From the 1st to the 7th of January 2024

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) 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.

Preconceptional 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 NTDs-affected pregnancies risk, and it requires no change in diet or behaviour."

Moreover, this year IF provides examples of food fortification which highlights the importance of implementing the WHA76.19 resolution "Accelerating efforts for preventing micronutrient deficiencies ... and effective food fortification".

For this occasion, IF organises and invites you to the webinar "Let's Thrive Impact!" on January 5, 2024 including speakers from all over the world sharing their perspectives on how we can build a smarter, stronger, and healthier future for all through food fortification implementation.

For more information about the WFAAW24 webinar, visit the IF website.

JOIN THE WFAAW 2024 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.

Scan the barcode or visit https://bit.ly/WFAAW24 to join.

The adopted WHA76.19 Resolution 'Accelerating efforts for preventing micronutrient deficiencies and their consequences, including spina bifida and other NTDs, through safe and effective food fortification' urges Member States to make decisions on food fortification with micronutrients and/or supplementation. By fortifying the most appropriate food sources with folic acid, such staple food, millions of birth defects can be prevented in an extremely cost-effective way. During WFAAW and the 'Let's Thrive Impact Now' webinar, the importance of implementing the WHA76.19 resolution on food fortification was emphasised, and strategies for food fortification were discussed.

To sustain this momentum in 2024, the webinar panelists took the opportunity to rethink how the world tackles malnutrition and prevents NTDs. The panel featured experts such as Oliver Camp (Senior Associate,Global Alliance for Improved Nutrition - GAIN), Dr. Ayoud Al-Jawaldeh (Regional Adviser in Nutrition, WHO-EMRO), Dr. Amina Barkat (Neonatologist, University Mohammed V Rabat Morocco), Dr. Salima Al Mammary (Director of Nutrition, Ministry of Health Oman), Dr. Kribanandan Gurusamy Naidu (Chair, Rotary District Action Group for SBH; Vice President, IF member association in Malaysia, SiBIAM), Dr. Jeffrey Blount (Pediatric Neurosurgeon, Children's Hospital of Alabama; Chair of GAPSBi-F Consortium), Scott Montgomery (Director, Food Fortification Initiative - FFI), and Raymond Chikomba (Senior Nutrition Specialist, Southern African Development Community).

World Birth Defects Day

On March 3, IF joined the global community in commemorating the 9th edition of WBDD with the theme ‘Every Journey Matters!’. In support of this day, IF promoted resources and advocacy messages to raise awareness on birth defects.

Alongside an esteemed panel of advocates from the WHO, Children's HeartLink, Operation Smile, MiracleFeet, the Centers for Disease Control and Prevention, and the Global Alliance for Rheumatic and Congenital Hearts, IF amplified awareness of birth defects, preventive measures, and advancements in care and treatment during the WBDD webinar on March 4.

International Siblings Day

Celebrating Siblings Day on April 10, 2024, IF honoured the brothers and sisters of individuals affected by SBH. This occasion serves as a testament to the unique and unbreakable bond shared among siblings, marked by unwavering love and mutual support.

To enhance the significance of this day, IF released a toolkit featuring guidelines for individuals to engage, comprising a template for accompanying images and a selection of hashtags for social media use. Many of the SBH communities along with their siblings participated in the Siblings Day, sharing photos and videos to promote the message that siblings are lifelong best friends that make each other smile every day.

Global Day of Parents

CELEBRATION OF

PARENTS DAY

JUNE 1

Let's shape the SBH community! Send us your contributions in one of the next ways:

Story and photo

Photo

Video

On June 1, 2024, IF commemorated the UN designated Global Day of Parents to recognise, highlight, and celebrate the important role that parents play in nurturing and raising children. Families, parents and caregivers rear and protect children in their first steps being their advocates and an integral part of our community.

This year marked IF's first participation in the Global Day of Parents, specifically honoring parents of children affected by SBH. Caring for a child with SBH requires dedication, resilience, and access to specialised treatment and care, often presenting additional challenges, particularly in societies that are not yet fully inclusive. IF acknowledged and celebrated parents, recognising both the difficulties they face and the joy they share in supporting and growing alongside their children.

HAPPY PARENTS DAY

We are the Ng'arus and we love travelling.

Almost twelve years ago we were blessed with this beautiful daughter, Kyla.

READ OUR STORY

Raphaella Wong

"My parents always try hard to provide me with the best care.

I enjoy travelling, swimming, playing games and building sandcastles with mum and dad.

They love me lots and are always there when I am unwell or need them most."

HAPPY PARENTS DAY

My name is Amie, I was born with Spina Bifida myelomeningocele.

This is our story of our son Oliver born in 2020

READ OUR STORY

Su Xiao Vin

"My precious travel mates are my parents.

We travel and explore different places at my pace and capacity.

They are my greatest supporter and encourager to persevere in all circumstances."

International Youth Day

On August 12, 2024, in celebration of International Youth Day, the IF International Youth Group SBH launched a global social media campaign, inviting young people with SBH to amplify youth voices and raise awareness on the theme 'Mental Health Matters'.

Recognising independent living as a fundamental right under Article 19 of the UNCRPD, the campaign highlighted the critical role of mental health in supporting youth through the transition from adolescence to adulthood. The IF International Youth Group SBH addressed key topics such as the impact of friendships, sports and exercise, body confidence, self-esteem, and overall physical health. Through a survey, group members selected 'disability acceptance' as the primary focus for the year, emphasising the importance of self-empowerment and social inclusion.

I remember the challenges my family and I faced, and I'm hopeful for a future where every mother can have a healthy baby, and every family can enjoy a peaceful and happy life.

Dr. Nebiyat Tesfaye, Ethiopia
Personal Life Experience

it's important to focus on the positive things or the things that you surely can do. Even if they are small you have to focus on those things.

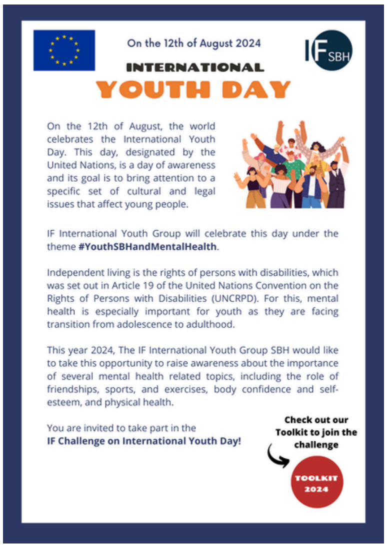
Jurn Anthonis, Belgium
Improving Self-Acceptance

Always conduct and encourage peer to peer support so as you learn from shared experiences and knowledge.

Ajok Proskovia, Uganda
Youth Advocacy

I know its hard having spina bifida, hydrocephalus and other disabilities but you have to learn to love yourself

Rereloluwa Adelou, Nigeria
Motivation For Youth



On the 12th of August 2024

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 **#YouthSBHandMentalHealth**.

Independent 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). For this, mental health is especially important for youth as they are facing transition from adolescence to adulthood.

This year 2024, The IF International Youth Group SBH would like to take this opportunity to raise awareness about the importance of several mental health related topics, including the role of friendships, sports, and exercises, body confidence and self-esteem, and physical health.

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

Check out our Toolkit to join the challenge

TOOLKIT 2024

INTERNATIONAL
YOUTH DAY
TOOLKIT 2024

#YouthSBHandMentalHealth
STORY OF MY LIFE
REBECCA AUSTIN, AUSTRALIA

#YouthSBHandMentalHealth
Malik Armughan Ali
Pakistan

We got an illness that affects your heart, your leg, or your brain. That skill is a sickness affecting the body and there should be no difference. Feelings of severe despondency anxiety and panic attacks are not symptoms of weakness they are symptoms of trying to remain strong for far too long.

#YouthSBHandMentalHealth
Kateryna Shcherbyna,
Chair IF International Youth Group SBH,
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.

#YouthSBHandMentalHealth
Mirela Bukovac,
Croatia

It's okay not to be okay

#IFInternationalYouthDay
#YouthSBH
#YouthSBHandMentalHealth
#YouthSBHVoice

International Day of Older Persons

INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

On the 1st of October 2024

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 that day, the International Federation for Spina Bifida and Hydrocephalus (IF) 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.

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

For any additional question, please contact info@ifglobal.org

On October 1, 2024, IF, together with its members, celebrated the IDOP, a day formally recognised by the UN to honor the contributions and challenges of older individuals worldwide.

With advancements in treatment and care, many individuals born with SBH are now reaching their senior years. However, there remains limited knowledge about the impact of ageing with SBH on physical health, cognitive abilities, and independence. Understanding and addressing these challenges is a key objective for IF.

On this occasion, IF highlighted the lived experiences of older persons with SBH, drawing attention to the obstacles they face and the urgent need to address them. As part of its advocacy efforts, IF also continued to disseminate publications on best practices for ageing with SBH, promoting awareness and solutions for a more inclusive future.

International and European Days of Persons with Disabilities

During the EDPD and the IDPD in November and December 2024, IF actively advocated for the rights of individuals with SBH and their families, supporting the EU's implementation of the ESRPD and UNCRPD. The campaign took place in a hybrid format, combining in-person and virtual events.

The EDPD, an annual conference organised by the European Commission in partnership with the European Disability Forum (EDF), featured debates with policymakers, experts, and advocates. Held on December 28-29 in Brussels, the conference focused on the second phase of the European Strategy on the Rights of Persons with Disabilities, emphasising independent living and accessible cities; key priorities for IF.

On December 3, IF celebrated the IDPD by hosting a hybrid event that included the 1st Euregional Youth Meeting in Limburg, Netherlands. Organised by IF International Youth Group SBH (Brussels) and Zonnebloem JONG Westelijke Mijnstreek (Netherlands), the event brought together young people with disabilities from Belgium, Germany, France, Poland, and the Netherlands. Through interactive discussions, participants exchanged experiences on independent living, highlighting the importance of cross-border collaboration and youth-led initiatives.

STRENGTHENING CARE THROUGH COLLABORATION

MENTAL HEALTH IN FOCUS

- What is mental health?
- Mental health: prevalence and causes;
- Chronic illness: prevalence and comorbidities;
- Mental health for children/adolescents affected by SBH;
- Mental health and clinical adaptations;

Mental Health Matters
Spring Webinar for Parents
May 24 - 3pm (CEST)
Translation available

SPEAKER

Meet the Expert

Prof. Dr. Alexander von Gontard
Child and Adolescent Psychiatrist

Parent-Child and Adolescent Department,
Hochgebirgsklinik, Davos, Switzerland

Governor Kremers Centre, Department of Urology,
Maastricht University Medical Centre, Maastricht, The Netherlands

Mental health encompasses emotional, psychological, and social well-being, influencing how individuals think, feel, and behave. Recognising the importance of this topic, IF facilitated multiple dialogues throughout the year upon request from its members.

As part of these efforts, participants had the opportunity to engage with a leading expert in the field, Prof. Dr. Alexander von Gontard. Through these interactive sessions, attendees gained insights into mental health challenges, risk and protective factors, and best practices in supporting individuals with SBH.

Recommendations on urological guidelines included conducting cognitive assessments before school entry to identify strengths and weaknesses, as well as performing neurological evaluations. Additionally, screening for psychological disorders was advised, with follow-ups by professionals in case of positive findings. Counseling was highlighted as a recommended intervention, with further treatment options such as psychotherapy if necessary.

Professor von Gontard concluded that mental health care is effective and can support families through challenging times. Following his presentation, a brief Q&A session covered topics such as overprotective parenting, building confidence, and the significance of mental health for both youth and the ageing SBH community.

IF Youth Webinar Mental Health Matters

On August 12, the IF International Youth Group SBH organised a webinar titled 'Mental Health Matters' to raise awareness for IYD and engage the global youth SBH community. The webinar featured an invited expert presentation by Prof. Dr. Alexander von Gontard, who discussed mental health, coping mechanisms, mindfulness, and the latest advances in the assessment and treatment of mental health disorders, particularly those specific to SBH.

MENTAL HEALTH MATTERS WEBINAR
International Youth Day 2024

MEET THE SPEAKERS

INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

Kateryna Shcherbyna, Ukraine
International Youth Day 2024

Nebiyat Tesfaye, Ethiopia
Personal Life Experience

Laura Rosillo Beneyto, Spain
Mental Health Matters

Jurn Anthonis, Belgium
Improving Self-Acceptance

Prof. Dr. Alexander von Gontard
Mental Health Expert

Ajok Proskovia, Uganda
Youth Advocacy

Members of the IF Youth Group SBH also shared their personal experiences and coping strategies. Laura Rosillo Beneyto highlighted the topic of ‘Disability Acceptance’ and its multidimensional nature, while Dr. Nebiyat Tesfaye shared his journey to becoming a neurosurgeon and advocating for the rights of those with SBH. Jurn Anthonis emphasised the importance of self-acceptance and a positive support system, and Ajok Proskovia encouraged youth to actively engage in advocacy and raise awareness.

World Birth Defects Day Webinar

During the WBDD webinar on March 4, IF joined an esteemed panel of advocates from the WHO, Children's HeartLink, Operation Smile, MiracleFeet, the Centers for Disease Control and Prevention, and the Global Alliance for Rheumatic and Congenital Hearts to amplify awareness of birth defects, preventive measures, and advancements in care and treatment.

Speakers highlighted current knowledge, gaps in research, and the need to set priorities for both the short and long term to promote health equity for birth defects. IF underscored the barriers to healthcare that leave the SBH community behind, emphasising that while these challenges are complex, the right to live without barriers of discrimination is fundamental and non-negotiable.

ADDRESSING BIRTH DEFECTS INEQUITIES

PREVENTION, LIFESAVING AND LIFELONG CARE

Monday, March 4, 2024

8AM EST | 2PM CET | 6:30PM IST

Register: https://bit.ly/492K5Z2

Leading organizations and patient advocates discuss:

- **Advancing access**
- **Successful advocacy**
- **Capacity building strategies**

Congenital anomalies cause 10% of all newborn deaths; 6% of all post-neonatal under 5 deaths and 8% of all under 5 deaths.

Those who survive are at risk of lifelong disability if they don't have timely access to high-quality care.

The burden of death and disability is disproportionately high in low- and middle-income countries.

With remarks from Dr. Anshu Banerjee
Dir., Dept. of Maternal, Newborn, Child and Adolescent and Ageing
World Health Organization

One year after the WHA76.19 Resolution

This year of 2024 marked the seventy-seventh World Health Assembly (WHA77) where we celebrated one year one year after the WHO Executive Board (WHO EB) decided to recommend to the WHA76 the adoption of the following draft 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 behalf of the global SBH community, IF Secretary General – Dr. Sylvia Roozen urged Member States and partners during the WHA77 to leave no one behind.

Urgent actions are needed to ensure social protection for food security and nutrition in order to leave no one behind. **Nothing About Us Without Us**

Dr Sylvia Roozen
IF Secretary General
At the Seventy-seventh World Health Assembly, Geneva

#WHA77

WHA77 Side Event Congenital Anomalies and Universal Health: Leaving No One Behind

The WHA, following the UN High-Level Meeting on Universal Health Coverage, provides an opportunity to assess global progress on health for all. However, the needs of individuals with congenital anomalies requiring specialised healthcare are often overlooked in universal health coverage designs. While some countries have made strides in prioritising specialised care, more efforts are needed for true universal coverage.

To address this, IF, in collaboration with several global health organisations, hosted a WHA side event titled ‘Congenital Anomalies and Universal Health: Leaving No One Behind’ on May 27, 2024, in Geneva. The event aimed to advocate for policies and investments that ensure access to prevention and care for those with congenital anomalies. Discussions focused on integrating congenital anomaly screening and management into national policies to meet SDG 3 targets, improve access to essential medicines, and expand financial protection for treatment.

Key recommendations for policymakers included:

- Include the needs of individuals with congenital anomalies in universal health care programs;
- Raise awareness of their rights and dignity in line with the UNCRPD;
- Increase investments for lifelong prevention and care, including the transition to adulthood;
- Involve persons with congenital anomalies and their organisations in policy-making;
- Address barriers to healthcare access, including attitudinal, physical, policy, and social challenges.

ERN-ITHACA Working Group Spina Bifida & other Dysraphisms

Within the European Reference Networks (ERNs), IF represents the patient community for individuals with SBH. ERNs are networks of healthcare providers across Europe, focused on rare and complex diseases that require specialised treatment. IF is an active partner in ERN-ITHACA, which covers rare malformation syndromes, intellectual and neurodevelopmental disorders. IF participates in the ERN-ITHACA working group on spina bifida and the Patient Advocacy Groups (ePAG), representing the SBH community and bridging communication between patients and the ERN.

In 2024, a workshop was held to discuss the updated ORPHANET classification as well as future research and innovative diagnostics and treatment from the perspectives of genetics and urological management. To strengthen the pediatric urological guidelines for Spina Bifida, IFcontinued its broader collaboration with the European Association of Urology (EAU), ERN eUROGEN, and ERN ITHACA. During the 30th International Conference on Spina Bifida and Hydrocephalus, the chairperson of the guideline panel, Prof Dr. Christian Radmayr, provided his reflections on this unique multidisciplinary collaboration which actively involves persons with SBH, as well as their families. The launch of this publication is planned for early 2025.

EU-Ukraine Webinar Series

Since 2023, IF has collaborated with the ERN ITHACA Working Group on Spina Bifida, ERN eUROGEN, and OMNI-Net Ukraine to create a series of webinars focusing on multidisciplinary care for Spinal Dysraphisms. ERN-ITHACA serves as a European reference network specialising in rare malformation syndromes and intellectual and neurodevelopmental disorders. IF, acting as the international representative organisation, officially represents individuals with SBH within this network. In this capacity, IF advocates for the needs of individuals with SBH and works to strengthen partnerships to enhance multidisciplinary care. For this collaborative effort, IF also partnered with ERN eUROGEN, dedicated to rare urogenital diseases and complex conditions, and OMNI-Net Ukraine, a network consisting of more than 20 children's hospitals in 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, Nataliia 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 Njiman
2: Neurogenic bladder classification, pathophysiology, diagnosis

08.02.24 – Rien Njiman
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

Funded by the European Union

The first webinar series, spanning from November 2023 to April 2024, comprised nine sessions. At the onset of the series, clinicians from Europe and Ukraine convened to exchange knowledge and best practices regarding Spinal Dysraphisms. The second webinar series started in November 2024 and will continue into 2025.

THE 30th INTERNATIONAL CONFERENCE ON SPINA BIFIDA AND HYDROCEPHALUS

The 30th International Conference on Spina Bifida and Hydrocephalus, titled 'Bridging the Healthcare and Prevention Gaps – A Multidisciplinary Team Approach with the Community at Heart,' was held from October 24 to 26 in Kuala Lumpur (Petaling Jaya, Selangor). The event was organized by the Spina Bifida & Hydrocephalus Association of Malaysia (SIBIAM) in partnership with the International Federation for Spina Bifida and Hydrocephalus (IF).

CONFERENCE COMMITTEES

The success of this conference can be attributed to the commitment and leadership of the following individuals and their teams, who worked relentlessly to create a platform that encouraged meaningful discussions, knowledge exchange, and networking opportunities for all attendees. From the local organising committee: Prof. Dr. Amaramalar Selvi Naicker (President of SIBIAM and Chairperson of the National Organising Committee), Ir. Dr. Kribanandan Gurusamy Naidu (Co-Chair of the National Organising Committee and Chairperson of DASH, and Vice President of SIBIAM), Dr. Chua Li Shun (Sibiam and conference committee member), Dr. Chan Yean Koon (Sibiam and conference committee member), Ms Mahesvari Vardaraju (SIBIAM admin manager). From the International Scientific Conference Committee: Dr. Sylvia Roozen – IF Secretary General (chair), associate Professor Dr. Ohnmar Htwe @ Rashidah Ismail (chair local scientific committee), associate Professor Dr. Wong Sau Wei (co-chair local scientific committee), Prof. Dr. Richard Finnell, Prof. Dr. Jacques Scheres, Dr. Quentin Johnson, and Dr. Eva Bermejo Sanchez.

Organised by:

Supported by:


E-SOUVENIR
PROGRAMME

The 30th
International Conference On
Spina Bifida & Hydrocephalus

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

24 - 26
October 2024

AVANTÉ Hotel, Petaling Jaya, Selangor
Greater Kuala Lumpur, Malaysia

sbhconference2024.com

Conference Programme Book

Together with the international scientific conference committee, a conference programme book was developed to provide important information on the conference agenda, presentation abstracts, introduction to the conference keynote speakers and faculty, opportunities for engagement through workshops, visibility for sponsors, and the conference logistical information.

Conference Participants

For the first time, this 30th International Conference built a new bridge between health professionals, researchers, individuals living with SBH, their families, and emerging scholars to discuss strategies for addressing gaps in healthcare and prevention, while promoting a multidisciplinary approach that placed community at its core. Contributions were received from across the globe, representing a wide array of perspectives and shared experiences.

Conference Highlights

The conference aimed to close the gaps in healthcare and prevention while embracing a multidisciplinary approach centered on the community.

One of the standout features was the remarkable interaction between various stakeholders, building new bridges between healthcare professionals, researchers, individuals living with SBH, their families, and emerging scholars. This platform encouraged open discussions on strategies to tackle healthcare and prevention gaps, emphasising a collaborative approach that places the community at the forefront.

"Bringing together the global SBH community, this pivotal conference fostered essential exchange of knowledge, experiences and best practices whilst highlighting multidisciplinary and preventive approaches. Prioritising quality of life and holistic wellness reinforced our collective commitment to ensuring the voices of individuals with Spina Bifida and their families remain central to care".

Prof. Dr. Amaramalar Selvi Naicker – President of SIBIAM

"For the 1st time, this 30th International Conference on Spina Bifida and Hydrocephalus builds new bridges between health professionals, researchers, individuals living with SBH, families, emerging scholars, industry partners, and policy makers to advance disability inclusion leaving no one behind".

Victoria Sandoval – IF President

"Having a Global presence at the conference with almost 330 delegates with over a 1/3 from overseas, provided for sharing incredible experiences with a clear impetus to collectively move the SBH agenda forward. The extent of developments in multidisciplinary care and the strides made in terms of prevention worldwide, shared throughout the 3-day conference, provided a clear direction forward. The close linkages made by SIBIAM to Rotary Clubs locally through DASH and the success of the Global Grant Initiative, provides a beacon of hope for collaborative action which can be easily emulated worldwide to strengthen contributions to SBH care and prevention".

Dr. Kribanandan Gurusamy Naidu – Chair of the Rotary District (3300) Action Group for SBH (DASH) and Vice-President of SIBIAM

"The conference proceedings reflect progress on key areas on prevention, scientific knowledge and multidisciplinary care. While each one of us can make a difference, only together we make change".

Dr. Sylvia Roozen – IF Secretary General

The diversity of session formats, keynote lectures, parallel sessions, roundtable discussions, poster viewings, forums, and workshops fostered meaningful engagement among participants. The broad range of topics covered, from managing neurogenic bladder and bowel to maximising mobility and functional activities, addressing psychological health, sexual health, reproduction, nutrition, wellness, and advocacy, sparked dynamic conversations that shaped collective priorities.

A key highlight was the special focus on the SBH associations through country update presentations. This provided an opportunity to spotlight local initiatives and progress.

The program also embraced intersectionality, encouraging discussions relevant to youth, the aging population, women with disabilities, intergenerational learning, and strengthening advocacy in alignment with the UNCRPD.

Another key element was the strong emphasis on cross-cutting themes such as multidisciplinary care and independent living. For example, sessions on urological management included critical discussions on mental health, and the workshop on large-scale food fortification integrated genetics, offering new perspectives on prevention.

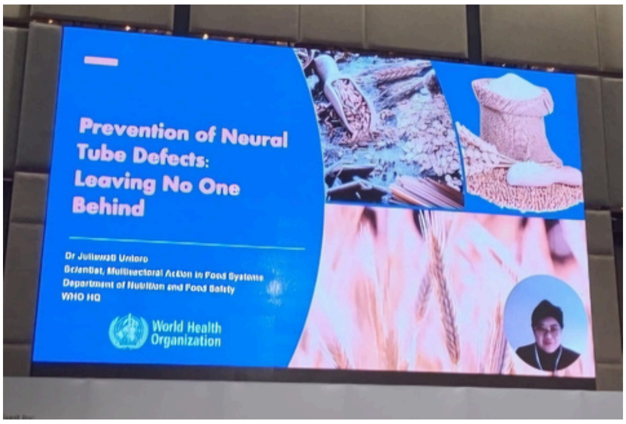
The conference culminated in the Kuala Lumpur Declaration, a significant outcome that outlined commitments made by participants. Additionally, to celebrate the WSBHD, global engagement was achieved through hybrid means, bringing colorful contributions from around the world via photos, videos, text, and a live-streamed webinar.

Partnerships were forged and strengthened throughout the event. A key moment was the workshop on large-scale food fortification, where public sector representatives (e.g., WHO, WFP, Ministry of Health Malaysia, academic scientists), private sector partners (e.g., premix suppliers), and civil society members (SBH advocates and healthcare professionals) discussed measures to prevent micronutrient deficiencies in support of future work in Malaysia and beyond.

This conference not only provided a platform for valuable dialogue but also paved the way for continued collaboration, commitment, and progress in the SBH community worldwide.

Conference Keynotes

The conference invited two keynote speakers prioritising two topics on prevention and genetics. In the first keynote lecture by Prof Dr. Rick Finnell (distinguished Professor of Paediatric Genetics, Baylor College of Medicine, USA), the biology of Neural Tube Defects was shared with reflections from prevention efforts to stem cell therapeutics. In the second keynote lecture, Dr. Juliawati Untoro (scientist at the Multisectoral Action in Food Systems Unit of the Department of Nutrition and Food Safety, WHO Headquarters in Geneva, Switzerland) gave an inspiring lecture on the prevention of NTDs: Leaving No One Behind.


Prevention of Neural Tube Defects: Leaving No One Behind

Dr Juliawati Untoro
Scientist, Multisectoral Action in Food Systems
Department of Nutrition and Food Safety
WHO HQ

World Health Organization

Conference Participation IF Advisory Groups

Special emphasis was placed on the contributions of the youth group and the working group on ageing through various plenary sessions and parallel workshops. These included the forum on ageing presented by past and current IF Presidents, video contributions during the forum, the youth forum ‘Stronger Together’, the youth workshop ‘Becoming an Advocate in Your City’, participation in plenary panel discussions, presentations on youth involvement in local research during a country update session, an international youth group presentation in a parallel session, sharing testimonials of lived experiences during a workshop to promote regional LSFF, networking in breakout sessions, and a youth member becoming recipient of the SBH Global Lifetime Achievement Award. Additionally, reflections from both groups were incorporated into the Kuala Lumpur Declaration, ensuring that the conference addressed the key priorities of both younger and ageing communities.

Conference Awards

To honor exceptional contributions, awards were presented in three categories with its recipients as follows. For the Global Healthcare Professional Hero Award: Assoc Prof Dr. Volodymyr Gonchar (Ukraine), Ms Ruth Nalugya (Uganda), Ms Norazah Haron (Malaysia), Dr. Ong Lai Choo (Malaysia). For the Global Lifetime Achievement Award: Mrs Ayu Primarini (Indonesia), Dr. Nebiyat Tesfaye Hailemariam (Ethiopia), Dr. Yang Mee Eng (Malaysia).

During each international conference, IF presents the IF Award to an individual or organisation in recognition of their special contribution to the service of people with disabilities in general or to people with SBH in particular. In 2024, Prof. Dr. Rick Finnell received the Award of Excellence.

Conference in Numbers

The meeting truly embodied the spirit of an anniversary conference, with impressive final attendance numbers and statistics. Nearly 330 individuals registered from 30 countries, excluding online participants, volunteers, vendors, and others, marking an outstanding achievement. Among them were around 200 local participants, including doctors, allied health professionals, SBH families, and Rotarians. The conference took place over three days in Kuala Lumpur, Malaysia, and featured two keynote speakers, 107 faculty members, 88 sessions, 14 workshops, 4 forums and roundtables, over 12 posters, and more than 71 oral presentations. During the closing Stars & Strides evening, we also had the pleasure of welcoming 36 partners and sponsors, which was truly remarkable.

What made it even more gratifying was the participation of 125 delegates from 30 countries. Notably, IF President Victoria Sandoval, who herself lives with SB, traveled nearly 40 hours from Guatemala to join the conference. Support from neighboring countries was also incredibly strong, with large contingents from Indonesia, India, and Australia, with 25, 23, and 12 delegates, respectively, attending the conference.

A warm thank you to all conference organisers, participants, partners, and sponsors in making this anniversary conference a success together!

WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY

Established and designated by IF General Assembly in Guatemala 2011, the WSBHD on 25 October is a yearly event that serves to raise awareness of the rights and needs of the SBH community as well as the UNCRPD.

WSBHD Theme ‘Bridging Gaps Together’

Each year, IF members select a different theme for WSBHD. Despite progress, individuals with SBH still face numerous challenges, including stigma, discrimination, and a lack of awareness, all of which further hinder their ability to fully engage in life's opportunities. In response, the WSBHD24 focussed on the theme ‘Bridging Gaps Together,’ complementing the 30th International Conference on Spina Bifida and Hydrocephalus ‘Bridging the Healthcare and Prevention Gaps - A Multidisciplinary Team Approach with the Community at Heart’.

WSBHD Webinar

For the first time, IF successfully organised the WSBHD webinar in a hybrid format, with 333 participants attending the conference in person in Malaysia from 29 countries, and 32 joining the event online via the conference webinar.


INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY

CONFERENCE

On October 25th we look forward celebrating the World Spina Bifida and Hydrocephalus Day 2024 (WSBHD24) together with you during the WSBHD24 Conference!

During the WSBHD Conference, IF members from the regions Africa, Americas, Asia-Pacific, and Europe will share how their associations “Bridging Gaps Together” for this year’s WSBHD24! You are warmly invited to join us during this edition of the World Spina Bifida and Hydrocephalus Day!

OUR PANELISTS

Victoria Sandoval
President International Federation for Spina Bifida and Hydrocephalus

Dr Sylvia Roozen
Secretary General International Federation for Spina Bifida and Hydrocephalus

Hassan Funmilajo
Spina Bifida Hydrocephalus Association of Nigeria

Terezia Drdul
Slovenská spoločnosť pre Spina Bifida a/ alebo Hydrocefalus Slovakia

Elena Zappoli
Asociación para Espina Bífida e Hidrocefalia Argentina

Kateryna Shcherbyna & Dr Nebiyat Tesfaye
Youth Representatives IF International Youth Group SBH

TO REGISTER SCAN ME

WEBINAR DETAILS :

Friday 25th of October 2024

3.00 PM CEST (Brussels timezone)
9.00 PM MYT (Malaysia timezone)
10.00 AM ART (Argentina timezone)

Online, Zoom
Registration: https://bit.ly/WSBHD24conference

Visit → www.worldspinabifidahydrocephalusday.com

During the webinar, nine speakers from the African, Latin American, Asia-Pacific, and European regions were invited to share how their associations are working to bridge gaps and advance the rights of individuals with SBH.

A key theme of the webinar was that health is a vital aspect of social inclusion, encompassing both physical and mental wellbeing, which enables full participation in social and economic life. Ensuring equitable access to quality healthcare, preventive services, rehabilitation, and psychological support is crucial for allowing individuals, regardless of health conditions or disabilities, to live active, inclusive, and dignified lives. Essential elements of health as a tool for social inclusion include equal access to healthcare, prevention and rehabilitation services, mental health protection, and a multidisciplinary approach to care.

WSBHD Campaign Contributions

The WSBHD was further amplified through a dynamic social media campaign that showcased the vibrant messages of the global SBH community. A total of 39 pictures, videos, and texts, each reflecting unique perspectives on inclusion, were gathered and extensively shared across IF's social media platforms, ultimately reaching over 44,800 people.

All contributions are showcased on the official WSBHD website: www.worldspinabifidahydrocephalusday.com

PICTURES


WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY
Bridging Gaps Together
WSBHD24 Contribution

- **Spina Bifida & Hydrocephalus Association of Northern Alberta**
Canada

www.worldspinabifidahydrocephalusday.com


WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY
Bridging Gaps Together
WSBHD24 Contribution

- **Mandy,**
Wendy on wheels
USA

www.worldspinabifidahydrocephalusday.com


WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY
Bridging Gaps Together

- **Erioluwa and Alaba**
SBHAN, Nigeria

www.worldspinabifidahydrocephalusday.com

VIDEOS


WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY
Bridging Gaps Together
WSBHD24 Contribution

- **Hope with Spina Bifida**, India

www.worldspinabifidahydrocephalusday.com


WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY
Bridging Gaps Together
WSBHD24 Contribution in English

- **Elena Zappoli**
Latin American Network for Spina Bifida and Hydrocephalus (RELAEBHI)

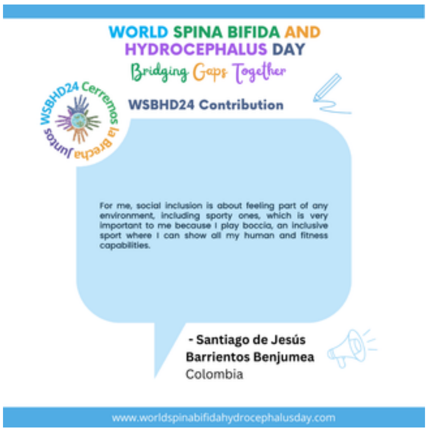
www.worldspinabifidahydrocephalusday.com

WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY
Bridging Gaps Together
WSBHD24 Contribution

- **Saya Ayu**
Indonesia

www.worldspinabifidahydrocephalusday.com

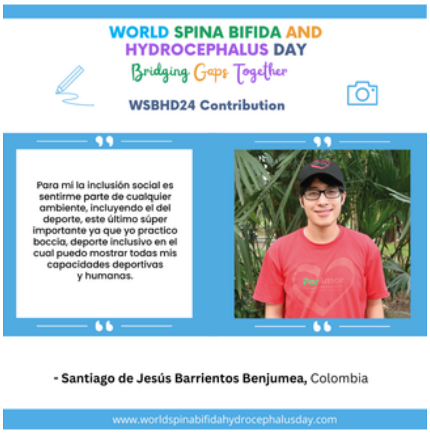
TEXTS


WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY
Bridging Gaps Together
WSBHD24 Contribution

For me, social inclusion is about feeling part of any environment, including sporty ones, which is very important to me because I play boccia, an inclusive sport where I can show all my human and fitness capabilities.

- **Santiago de Jesús Barrientos Benjumea**
Colombia

www.worldspinabifidahydrocephalusday.com


WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY
Bridging Gaps Together
WSBHD24 Contribution

Para mí la inclusión social es sentirme parte de cualquier ambiente, incluyendo el del deporte, este último súper importante ya que yo practico boccia, deporte inclusivo en el cual puedo mostrar todas mis capacidades deportivas y humanas.

- **Santiago de Jesús Barrientos Benjumea,** Colombia

www.worldspinabifidahydrocephalusday.com


WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY
Bridging Gaps Together
WSBHD24 Contribution

INCLUSIVITY

"Having equal opportunities in employment or skills upgrading with supportive working environment."

VINCENT CHUA
Malaysia

www.worldspinabifidahydrocephalusday.com

WSBHD24 ACTIVITIES

BY IF MEMBERS

IF member associations organised various side events and celebrated WSBHD24 in their own unique way, showcasing the strength of the global SBH community. More than 17 side events were organised, ranging from conferences, webinars, informal meetings, to outdoor activities. Below is a list of those events.

Spina Bifida and Hydrocephalus Belgium - BELGIUM
On Sunday 20 October, Spina Bifida and Hydrocephalus Belgium organised their annual autumn walk with their members. The walk took place in the beautiful nature of Belgium and the day concluded with a delicious shared meal. This year also commemorated the people that the association has lost over the last 45 years.

Featuring a selection of fabulous works created by our members along side other unique pieces. Join us in our National Office in Dublin all throughout this year's Spina Bifida Hydrocephalus Awareness Week to celebrate. Refreshments will be on hand all week long.

Spina Bifida Hydrocephalus - IRELAND
For Awareness Week this year, the Spina Bifida Hydrocephalus Ireland hosted several events around the theme: #SeeMyAbility-NotMyDisability. The highlight of the week was an Art Exhibition consisting of works made by their members, as well as donations.
They also hosted an online bingo, a webinar on transitioning to third-level education and a nationwide virtual 'Walk and Roll'.

Spina Bifida and Hydrocephalus Association - NIGERIA
On Saturday 26 October, the Spina Bifida and Hydrocephalus Association in Nigeria, organised a Spina Bifida and Hydrocephalus awareness walk. They also organised a media advocacy campaign on social media, on the radio and on TV, as well as an advocacy visit to hospitals on the need of multi-disciplinary health care for persons with SBH.

'Slovenská spoločnosť pre spina bifida a/alebo hydrocefalus - SLOVAKIA
On 12 October, the Slovenská spoločnosť pre spina bifida a/alebo hydrocefalus organised a screening of a documentary film that tells the stories of young people with disabilities.

Komunitas Spina Bifida Indonesia - INDONESIA
On 27 October, Komunitas Spina Bifida Indonesia organised a special webinar by inviting four expert speakers at once: Two neurosurgeons, a medical rehabilitation doctor and a professional physiotherapist.

On the 20th of September 2024

WORLD HYDROCEPHALUS DAY

In preparation for the World Spina Bifida and Hydrocephalus Day on October 25, 2024 we are loud on this year's theme: Bridging Gaps Together. A special message of support goes out to IF Member the Hydrocephalus Association US for awareness raising activities on September 20 as part of the #WorldHydrocephalusDay!

To the present, there are many barriers which individuals with Spina Bifida and Hydrocephalus face. With stigma, discrimination and lack of awareness creating further barriers to the full enjoyment of life. Join the global Hydrocephalus community this year in promoting:

"Bridging Gaps Together"

Hydrocephalus Association – USA
On 20 September, the Hydrocephalus Association in USA organised awareness-raising activities promoting accessibility for early diagnosis and treatment for individuals with undiagnosed or untreated hydrocephalus.

Spina Bifida and Hydrocephalus Scotland – SCOTLAND
For WSBH on 25 October, Spina Bifida and Hydrocephalus Scotland organised fund raising events and activities.

Spina Foundation – POLAND
On 28 September, Spina Foundation Poland organised an educational conference titled 'Brain – a command centre: neurodiagnostics, neurotreatment, neurorehabilitation of people with Spina Bifida'.

Spina Bifida and Hydrocephalus Association - UGANDA

The Spina Bifida and Hydrocephalus Association in Uganda created a report from the World Spina Bifida and Hydrocephalus Day commemoration and the events that took place to mark this special day.

WSBHD24 ACTIVITIES

BY IF MEMBERS

Paraguay

For the SB/H day «APAEBHI» prepares Prevention Meeting in reference Hospitals sharing flyers in Crowded Places.

Para el día de la EB/H APAEBI prepara una Reunión sobre Prevención en hospitales De referencia repartiendo volantes en lugares concurridos.

Asociación Paraguaya de Espina Bífida y patologías similares - PARAGUAY

For the WSBHD, the Asociación Paraguaya de Espina Bífida y patologías similares (APAEBHI) hosted a meeting on Prevention in hospitals and handed over awareness raising flyers.

APEBI Day Center

Persons with SB/H will meet in APEBI Day Center to share the International Day, October 25th from 2.00 pm till 6.00 pm with parents, friends, staff, doctors and the Board Members to discuss about Disability Situation and the lack of Folic Acid in flours in Argentina.

Las personas con SB/H se reunirán en el nuevo Centro de APEBI para compartir el Día Internacional, 25 de octubre desde las 14:00 hasta las 18:00 horas con sus padres, amigos, personal, médicos y los miembros de la Junta Directiva para hablar sobre la situación actual de la discapacidad y la falta de Acido Fólico en la Harinas in Argentina.

Asociación Para la Espina Bífida e Hidrocefalia - ARGENTINA

On 25 October, the Asociación Para la Espina Bífida e Hidrocefalia in Argentina organised a gathering of parents, friends, staff, doctors and Board members, at its Day Centre. Together they discussed the situation of persons with disabilities in Argentina.

Mexico RENAPRED

Federico Nuñez Perea and Stephanie Nuñez Iturrieta

On the EB/H Day they will have a talk with the new municipal president of Puebla about SB/H subject. They will carry out an empathy and inclusive campaign on social networks, promoting inclusive tourism

El Día de la EB/H tendrán una charla con el nuevo presidente municipal de Puebla sobre la Temática de la EB/H. Ellos harán una Campaña de empatía e inclusión en redes sociales, promoviendo el turismo inclusivo

RENAPRED - MEXICO

On the WSBHD, RENAPRED in Mexico had a discussion with the new municipal president of Puebla concerning SBH. They also carried out a social media campaign promoting inclusive tourism.

Ecuador: *Sarah Lizarzaburu* and *Patricia Rodríguez*

Support groups in *Guayaquil* and *Quito* cities. More than 60 families are working Together in dissemination in Prevention During this International Day by Zoom.

Grupos de apoyo en las ciudades de Guayaquil y Quito. Más de 60 familias Estarán trabajando Juntos sobre difusión En Prevención durante este Día Internacional.

Support groups in Guayaquil and Quito cities - ECUADOR

During the WSBHD, more than 60 families worked together to raise awareness about prevention.

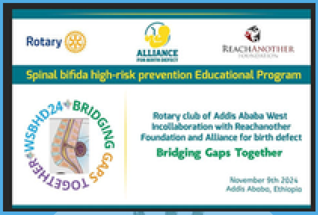
Panamá
Lara Arosemena

They are going on a press tour for the SB/H week.

Ellos van a llevar a cabo una gira de prensa durante la Semana de la EB/H.

Fundación Zero Limite Espina Bifida Panama - PANAMA

During the week of the WSBHD, the President of Fundación Zero Limite Espina Bifida Panama, Lara Arosemena, went on a press tour to talk to the media about SBH.



Spinal bifida high-risk prevention Educational Program

Rotary club of Addis Ababa West Incollaboration with Reachanother Foundation and Alliance for birth defect

Bridging Gaps Together

November 9th 2024
Addis Ababa, Ethiopia

Reach Another Foundation - ETHIOPIA

The Rotary Club of Addis Abeba West collaborated with the Alliance for Birth Defects and Reach Another Foundation to host a Parent Forum for families of children with SBH.

Coinciding with WSBHD, the event aimed to bring together 150 parents, including 50 children, to create a supportive community for sharing experiences and ideas while participating in recreational activities.

Asociación Dominicana de Espina Bífida e Hidrocefalia, Inc. - DOMINICAN REPUBLIC

For the WSBHD, the Asociación Dominicana de Espina Bífida e Hidrocefalia, Inc. launched a Prevention Campaign.

Dominican Republic

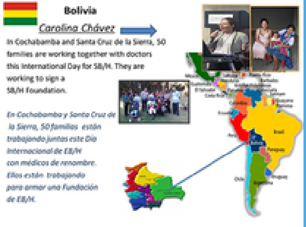
Luciano Moreta

They are opening a *Prevention* Campaign for SB/H Day.

Están abriendo una Campaña de Prevención en el Día Internacional De la EB/H.

Families of persons with Spina Bifida and Hydrocephalus - BOLIVIA

In Cochabamba and Santa Cruz de la Sierra, in Bolivia, 50 families worked together with doctors to build a foundation of Spina Bifida and Hydrocephalus.



Bolivia

Carolina Chávez

In Cochabamba and Santa Cruz de la Sierra, 50 families are working together with doctors this International Day for SB/H. They are working to sign a SB/H Foundation.

En Cochabamba y Santa Cruz de la Sierra, 50 familias están trabajando juntos este Día Internacional de EB/H con médicos de renombre. Ellos están trabajando para armar una Fundación de EB/H.

OMNI-Net - UKRAINE

On 23 October in Ukraine, OMNI-Net, the Khmelnytskyi City Children's Hospital and the Khmelnytskyi Rare Disease Center held a hybrid meeting for pediatric specialists. This was an opportunity to exchange experiences and resources on multidisciplinary care, such as recordings of the series of webinars by Omni-net, IF, ERN eUROGEN and Light of Spirit, reflecting meaningful exchanges between EU and Ukraine professionals.

COMMUNITY BUILDING AND TWINNING

IF ACTIVITIES WITH MEMBERS

MEMBERS MEETINGS

In 2024, IF held multiple meetings with its members to enhance the global SBH network, encourage knowledge sharing, and bolster collective advocacy efforts during international awareness days. Regional meetings played a significant role in expanding IF's membership, with eight new members joining during the IF General Meeting. The year began with an initial gathering of all members, reviewing past activities and setting priorities for the future. Additionally, IF organised regular board meetings and regional chapter meetings across Europe, the Americas, and the Asia-Pacific, fostering collaboration and communication among members. The IF communication coordinators' meetings also provided a platform for members to discuss key events and initiatives, such as WSBDH24 and the 30th International Conference for Spina Bifida and Hydrocephalus.

Four key meetings organised by IF provided important opportunities for member interaction and collaboration. These included the 30th International Conference on Spina Bifida and Hydrocephalus, where 13 member associations discussed their focus areas, and the EDPD, which brought together members from Serbia and Bulgaria to discuss regional priorities. Additionally, the Euregional Youth Meeting engaged young people with disabilities from multiple European countries in discussions on independent living and shared experiences. Finally, the Euregional Disability Summit strengthened regional cooperation, particularly with IF's member from Montenegro. These events helped promote the exchange of best practices and build stronger partnerships across IF's network.

IF Members Meeting, February 2024

WEBINARS

To strengthen the capacity of IF member associations and promote collaboration, a series of webinars was organised in spring and autumn. These sessions covered key topics relevant to the SBH community, including mental health, urological management, and spinal dysraphism. The webinars aimed to enhance knowledge, facilitate the exchange of best practices, and foster international cooperation among member countries

Recognising IF's priority on mental health, a dedicated webinar was organised for parents seeking to understand the fundamentals of mental well-being. Prof. Dr. Alexander von Gontard, a Child and Adolescent Psychiatrist from Hochgebirgsklinik, Davos, Switzerland, led the session. He provided insights into vulnerability and protective factors for mental health, offering valuable recommendations and guidance.

Building on the initiatives of 2023, IF continued its webinar series in collaboration with ERN eUROGEN (focused on rare urogenital diseases and complex conditions), ERN ITHACA, and OMNI-Net Ukraine, a network of over 20 children's hospitals in Ukraine. These sessions brought together clinicians from across Europe and Ukraine to exchange knowledge and best practices on Spinal Dysraphisms, further strengthening cross-border medical cooperation.

TRAINING

The annual thematic training for IF members, IF prioritised youth advocacy for its members aged 18 to 35. The training was conducted in two sessions.

Session I was an in-person gathering with youth participants from Belgium, France, Germany, Poland, and the Netherlands, fostering direct engagement and collaboration. Session II was an online follow-up meeting, open to the broader youth community, allowing for wider participation and knowledge exchange.

Both sessions were structured around the principles of the UNCRPD, with a particular emphasis on independent living. These principles formed the foundation of the training materials, equipping participants with the knowledge and skills to advocate for their rights effectively.

TWINNING

IF organised a total of five twinning meetings in 2024, aimed at fostering dialogue and building stronger connections across borders. These meetings provided a platform for peer-to-peer exchange, allowing member associations and individuals worldwide to share best practices, connect, and strengthen partnerships.

Key twinning opportunities in 2024 included the Euregional Youth Meeting, the WFAAW, the WHA77 side event, the Meet & Greet between IF's international youth and ageing groups, and the IYD webinar. Detailed descriptions of these meetings can be found throughout this annual report.

Moreover, in a separate interview article, paralympic gold medallist Jesper Pedersen and past president Cato Lie reflected on barriers and opportunities to achieve their ambitions and live a fulfilling life with SBH. A topic which is worth reading by both people with SBH and those without. The interview includes advice for people with SBH and demonstrates the physical and social barriers which they have encountered. Barriers that society as a whole needs to recognise and dismantle.

MEET THE SPEAKERS

Kateryna Shcherbyna, Ukraine
International Youth Day 2024

Nebiyat Tesfaye, Ethiopia
Personal Life Experience

Laura Rosillo Beneyto, Spain
Mental Health Matters

Jurn Anthonis, Belgium
Improving Self-Acceptance

Prof. Dr. Alexander von Gontard
Mental Health Expert

Ajok Proskovia, Uganda
Youth Advocacy

INTERVIEW

IF President Cato Lie meets paralympic gold medalist Jesper Pedersen

"Acessibility is necessary for some, like people with spina bifida and or hydrocephalus, yet it is good for everyone"
Cato Lie - IF President

Source: https://www.paralympic.org/jesper-pedersen

MEET CATO & JESPER

The President of the International Federation for Spina Bifida and Hydrocephalus (IF), Cato Lie, interviewed paralympic gold medalist Jesper Pedersen (24), on what it means to lead a happy, meaningful life, with disability.

Jesper won a gold medal in giant slalom and a bronze medal in the super combined sitting at the 2018 Winter Paralympics and five medals at the 2021 World Para Snow Sports Championships Jesper also won four gold and one silver medals at the 2022 Winter Paralympics. Lastly, Jesper took home four gold medals during the 2023 World Para Alpine Skiing Championships.

WORLD SPINA BIFIDA & HYDROCEPHALUS DAY

For Jesper, increased awareness of Spina Bifida and Hydrocephalus (SBH) is essential. The WSBHD is an opportunity to show that the diagnosis does not limit the SBH community and that many people with SBH can live a happy fulfilling life.

For Cato, it is important that, people with SBH are visible, given the opportunity to show how they celebrate life and to connect with the SBH community and stakeholders. This inspired IF's series of webinars on the need for an accessible world. Cato stated that he lives a good life with SB, and this disability should not stop one from leading a happy fulfilling life.

INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

5 January, 2024
9AM EST | 3PM CET | 10PM MYT
| Zoom Webinar

LET'S THRIVE IMPACT!

You are invited! Our champions on food fortification policies will offer their perspectives, and expert advice for a healthier, stronger, and smarter future for all

#WFAAW24 WEBINAR

OUR PANELISTS

Dr Sylvia Roozen
Secretary General International Federation for Spina Bifida and Hydrocephalus

Dr Ayoub Al-Jawaldeh
Regional Adviser in Nutrition WHO-EMRO

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

Dr Kribanandan Gurusamy Naidu
Chair of the Rotary District Action Group for SBH (D3300, 2019 onwards) and Vice President of SIBIAM

Oliver Camp
Senior Associate, Global Alliance for Improved Nutrition

Scott Montgomery
Director, Food Fortification Initiative (FFI)

Raymond Chikomba
Senior Nutrition Specialist Southern African Development Community

Dr Jeffrey Blount
Pediatric Neurosurgeon, Children's Hospital of Alabama, Chair of GAPSBi-F consortium

Dr Amina Barkat
Neonatologist University mohammed V Rabat Morocco

Dr Salima Al Mammary
Director of the Nutrition department in the Ministry of Health Oman

ACTIVITIES BY IF ADVISORY GROUPS

IF INTERNATIONAL YOUTH GROUP SBH

MEETINGS

The youth group of SBH represented 13 young individuals aged 18 to 35 from various countries, including the chair, Kateryna Shcherbyna (Ukraine), Laura Rosillo Beneyto (Spain), Ajok Proscovia (Uganda), Rereloluwa Adeolu (Nigeria), Mirela Bukovac (Croatia), Malik Armughan Ali (Pakistan), Rebecca Austin (Australia), Samuel Opeyemi (Nigeria), Patrícia Albertová (Slovakia), Nebiyat Testafaye (Ethiopia), Jurn Anthonis (Belgium), Chen Miaohua (Taiwan), and Harichandana Mynampati (India).

The group regularly organises online meetings to address crucial issues affecting the global youth SBH community. In 2024, the main focus of their discussions was mental health, an essential topic for the well-being of young individuals living with SBH.

CAPACITY BUILDING

The youth group identified several opportunities for organising capacity-building activities. A key meeting is highlighted below.

Youth Forum: Stronger Together

At the 30th International Conference on Spina Bifida and Hydrocephalus in Malaysia, the international youth group organised a Youth Forum: Stronger Together, focusing on sharing experiences of living with SBH, its impact on mental health, healthcare accessibility, and key challenges.

The forum discussed social isolation faced by wheelchair users due to inaccessible environments and stigmatisation. Participants identified priorities such as communication, representation, mental health, and healthcare. They emphasised the need for internet access, peer education, and learning from older individuals with SBH. Additionally, they proposed global surveys to assess challenges, advocated for a holistic approach to transition and care, and highlighted the importance of easy access to medical, sexual, and mental health support. Participants also expressed interest in work opportunities, relationships, and dating.

VISIBILITY

WSBHD24 What Does Inclusion Mean To You?

In celebration of WSBHD 2024, youth worldwide participated throughout October by sharing pictures, videos, and texts on the theme ‘What inclusion means to you’.

WSBHD24 Conference Webinar

IF Youth Group representatives, Kateryna Shcherbyna (Chair) and Dr. Nebiyat Tesfaye, served as speakers in the WSBDH24 Webinar, broadcasting live from Malaysia. They focused on the crucial topic of youth mental health, sharing insights into this year’s activities and future plans.

The 30th International Conference on Spina Bifida and Hydrocephalus

At the 30th International Conference, youth were given a prominent platform, participating in plenary sessions and parallel workshops. These included the ‘Stronger Together’ youth forum, the ‘Becoming an Advocate in Your City’ workshop, plenary panel discussions, and presentations on youth involvement in local research. Prominent youth representatives Kateryna Shcherbyna, Dr. Nebiyat Tesfaye, and Aveena Devi, also participated in an international group presentation, shared testimonials of lived experiences in workshops promoting regional LSFF, and engaged in networking sessions. Notably, Dr. Nebiyat Tesfaye received the SBH Global Lifetime Achievement Award. Additionally, reflections from youth were included in the Kuala Lumpur Declaration, ensuring the conference addressed their key priorities.

Raising Awareness during International Days

Young people with disabilities were recognised and celebrated during key awareness events, including International Youth Day, International Women's Day, World Mental Health Day, WSBHD24, and the International and European Days for Persons with Disabilities. During these occasions, the IF Youth Group SBH developed a special toolkit aimed at engaging the global community of young individuals with Spina Bifida and Hydrocephalus. These initiatives encouraged youth members to reflect on and share their personal experiences and perspectives on independent living, fostering awareness and inclusivity.

JURN ANTHONIS, BELGIUM

You want life to be as meaningful as can be. For me working and contributing to society is something that I need. Working with Spina Bifida is full of obstacles and during my student years I wanted do to a studentjob but not everything was practically possible for me. So I did a course to become a volunteer at summer camps. After I finished this course I started volunteering at summer camps for children without disabilities. A year later I focussed myself on summer camps for children with disabilities.

My tasks exists of organizing games and to taking care of the participants and help when they need it. Of course I can't help them with everything but I always try to help in the best way possible or I try to 'teach' them ways so that they can do it on their own. I really want to be a difference for the participants because I am in the same situation as they are. During the past ten years I did a lot of summer camps and I always came back home happy. This work is very meaningful and that's what keeps me going every summer again.

At those summer camps it's all about fun and being who you want to be. You can play games and have fun activities together. You can even talk about experiences with each other and so you can learn from each other. During a summer camp you don't have the feeling to be different. You don't think about your disability and that's the beauty of those summer camps.

"It also really sucks when medications don't seem to help a lot; when it doesn't make a big difference, take the hurt away or make things seem easy enough to get through each day. Treatment-resistant depression sucks so much - it feels like it swallows all my energy, leaves me sleeping so much and still feeling tired, stressed about so much of the stuff, alone and hopeless.

I have trialled a lot of different treatments without much success. I do keep trying and some may seem or be unconventional or unusual, but it is a battle that I am still fighting and I have to try what I can to get any bit of relief. Anyway, my point of my sharing this is to spread awareness and inform people. Things are not always as it seems. And we are always learning, so medical treatments are changing with new research - keeping an open mind whilst trialling things has been important and helpful to me. I'm grateful to the people who have been supportive during this long and painful time xx"
- Rebecca Austin - IF International Youth Group Member

"IT'S OKAY TO NOT BE OKAY"
- Mirela Bukovac

We got an illness that affects your heart, your leg, or your brain. That skill is a sickness affecting the body and there should be no difference. Feelings of severe despondency anxiety and panic attacks are not symptoms of weakness they are symptoms of trying to remain strong for far too long
- Malik Armughan Ali - IF International Youth Group Member

Contributions to Consultations

Consultation is a key aspect of incorporating youth voices, taking various forms from informal discussions to public consultations. In 2024, youth perspectives were integrated into policy actions through several initiatives. These included a 10-Point Action Plan for a More Inclusive Future, developed in collaboration with IDA, and the Kuala Lumpur Declaration, which highlighted youth priorities. Additionally, the IF Statement on Mental Health was shaped through consultation rounds with the IF International Youth Group, ensuring their voices were reflected in key decisions.

Call to Action on the Summit of the Future: don't leave youth with disabilities behind!

Our disabilities don't define us, but they do shape our experiences. Our voices matter and it is time for world leaders to listen listen and act accordingly

AJOK PROSCOVIA
IF Youth Representative to the IDA Youth Committee

Representing the SBH Community in IF Partner Organisations & Events

Youth group members actively represented the needs of the global youth community by participating in external meetings organized by partners such as the International Disability Alliance (IDA), EURORDIS – Rare Disease Europe, European Disability Forum (EDF), European Youth Forum (EYF), Mental Health Europe (MHE), and the World Health Organization (WHO). They engaged in meetings, training, workshops, and conferences, sharing the perspectives of the Spina Bifida and Hydrocephalus community. Notably, youth members took part in EDF and IDA youth committee meetings, European Youth Week, the Social Policy Action group of EURORDIS, a European Regional Disability Summit, and Rare Disease Week, gaining insights into European policies on rare diseases and raising awareness about SBH within broader disability and healthcare discussions.

IF WORKING GROUP ON AGEING WITH SBH

MEETINGS

In 2024, the IF Working Group on Ageing with SBH consisted of ten IF Member representatives: Kevin O'Donnell (Spina Bifida Hydrocephalus Scotland), Gerry Maguire (Spina Bifida and Hydrocephalus Ireland), Mario Sel (Vlaamse Vereniging voor Spina Bifida en Hydrocephalus vzw), Teije Dijk (Spina Bifida en Hydrocephalus Nederland), Eva Toft (Spin- Off), Jon Bateman (Individual member from Canada), and Chetan Shoraff (Spina Bifida Foundation India), Burhan Elli (Turkiye Spina Bifida Derneği), Jessica Schreiber (Individual member from New Zealand) and Jyoti Fernandes (Spina Bifida Foundation India).

KNOWLEDGE GATHERING

Meet & Greet: Youth & Ageing with SBH

In May 2024, IF hosted a 'Meet and Greet' session as part of its ongoing webinar series on Mental Health & Urological Management. This event brought together members of the IF International Youth Group SBH and the IF Working Group on Ageing with SBH, fostering dialogue and knowledge exchange on the unique challenges each group faces.

The session facilitated mutual learning by sharing diverse perspectives on mental health and urological management. It also served as a planning meeting for future initiatives, including two upcoming webinars designed to address the specific needs of both youth and ageing communities. These webinars aimed to provide targeted resources and support for mental health and urological care.

International Day of Older Persons

On October 1, the IDOP, IF raised awareness about ageing with SBH. Data shows that over 75% of newborns with SBH now reach adulthood, with numbers expected to rise. However, little is known about how SBH affects ageing, resilience, and independence.

IF emphasised the need for integrated care, as individuals with SBH experience accelerated ageing. They require access to multidisciplinary clinics, assistive devices, inclusive education, employment accommodations, and social protection to prevent financial hardship and institutionalisation. More research is needed on the impact of ageing and secondary conditions.

The IF Working Group on Ageing with SBH developed a toolkit for the awareness campaign, encouraging social media engagement by sharing personal stories and key messages to highlight challenges and advocate for better support.

WSBHD24 Conference Webinar

Dr. Kevin O’Donnell (Spina Bifida Hydrocephalus Scotland) and Gerry Maguire (Spina Bifida and Hydrocephalus Ireland), members of the IF Working Group on Ageing, spoke in the webinar, emphasising the need to better understand the lived experiences of older individuals with SBH.

Voices by
IF Working Group
on Ageing with SBH

Chetan Shoraff
Spina Bifida Foundation India

Gerry Maguire
Spina Bifida and Hydrocephalus Ireland (SBHI)

Kevin O’Donnell
Spina Bifida Hydrocephalus Scotland (SBHS)

The 30th International Conference on Spina Bifida and Hydrocephalus

At the 30th International Conference on Spina Bifida and Hydrocephalus in Kuala Lumpur, Malaysia, ageing with SBH was a key focus, especially during the Forum on Ageing. Presented by IF President Victoria Sandoval and past IF Presidents Cato Lie and Margo Whiteford, the forum addressed healthcare, accessibility, mental health, and stigma in different regions.

The IF Working Group on Ageing with SBH contributed through video testimonies. Dr. Kevin O'Donnell (SBHS) noted that, for the first time, a significant number of people with SBH have reached their sixties, underscoring the need to shape a better future for the ageing community. Gerry Maguire (SBHI) spoke on how low expectations impacted his mental health, urging prioritisation of well-being. Vanessa (SBAA) shared her journey overcoming her health prognoses, emphasising hope and perseverance. Chetan Shoraff (Spina Bifida Foundation India) reflected on his medical struggles, stressing the value of life and well-being.

NETWORK DEVELOPMENT

IF continues to strengthen and expand partnerships with relevant stakeholders to enhance the knowledge and understanding of SBH. In addition, IF promotes and encourages the adoption of effective treatment strategies and guidance in collaboration with these stakeholders. A key activity and core value remains the active inclusion of voices from individuals with SBH worldwide, aiming to improve the infrastructure for prevention and care.

For an overview of IF's network, both in Europe and internationally, please 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)**
- **Food Fortification Initiative Executive Management Team**
- **Human Rights and Climate Change Working Group**
- **International Disability Alliance (IDA)**
- **International Disability and Development Consortium (IDDC)**
- **Partnership for Maternal, Newborn and Child Health (PMNCH)**
- **Rare Diseases International (RDI)**
- **Scaling Up Nutrition Movement (SUN CSN)**
- **The Civil Society Engagement Mechanism for UHC2030 (CSEM)**
- **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 Cohort of Children with Congenital Anomalies (EUROlinkCAT)**
- **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 Organization (WHO)**

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)
- Child Help International
- CURE Children's Hospital Uganda (CCHU)
- CURE Zambia
- Festus Fajemilo Foundation, Nigeria (FFF)
- Katalemwa 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
- Neurokids
- 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 Commission
- GASPBi-F
- Global Alliance for Improved Nutrition (GAIN)
- Global Fortification Technical Advisory Group (GF TAG)
- 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
- World Health Organisation Regional Office for the Eastern Mediterranean

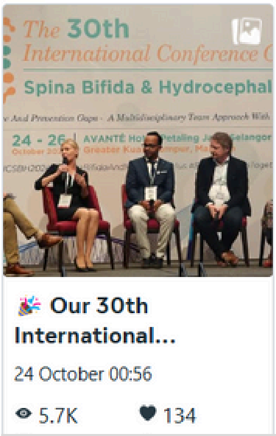
COMMUNICATIONS at a glance

Most impactful campaign
#WSBHD

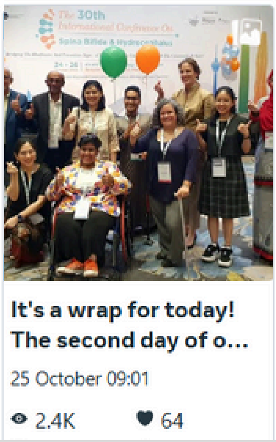
Facebook

7,9K
Followers

34,3K
People reached



🎉 Our 30th International...
24 October 00:56
👁 5.7K ♥ 134


It's a wrap for today! The second day of o...
25 October 09:01
👁 2.4K ♥ 64

🔔 Countdown to the World Spina Bifida a...
11 October 07:42
👁 1.6K ♥ 20

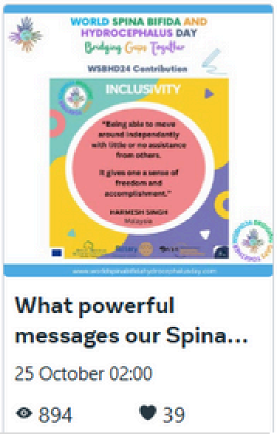
Instagran

834
Followers

11,9K
People reached


Celebrating #WSBHD24 with th...
29 October 04:32
👁 1.3K ♥ 70

Wardah, Cindy, Rani, Mikhaela and Bella...
25 October 05:00
👁 925 ♥ 34



What powerful messages our Spina...
25 October 02:00
👁 894 ♥ 39

X

3K
Followers

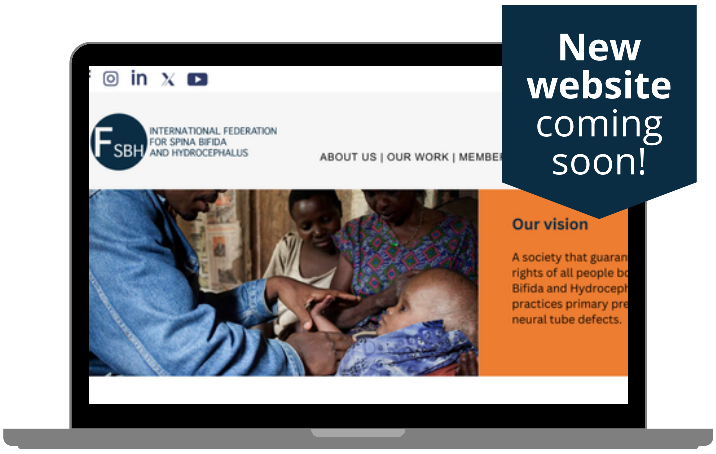
LinkedIn

1,5K
Followers

Newsletter

1,4K
Subscribers

New website coming soon!



Our vision

A society that guaran
rights of all people b
Bifida and Hydroceph
practices primary pre
neural tube defects.

CONTACT DETAILS

International Federation for Spina Bifida and Hydrocephalus (IFSBH)

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IFSBH

INTERNATIONAL FEDERATION
FOR SPINA BIFIDA
AND HYDROCEPHALUS