



INTERNATIONAL FEDERATION
FOR SPINA BIFIDA
AND HYDROCEPHALUS

ANNUAL REPORT 2022





2022

Date of publication: June 2023.

Cover page pictures: Pictures were obtained with permission of IF members.

Disclaimer: Co-funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the European Commission. Neither the European Union nor the granting authority can be held responsible for them.



Co-funded by
the European Union

TABLE OF CONTENTS

Foreward		6
<hr/>		
About IF	Who We Are	7
	Mission, Vision	7
	Values	7
<hr/>		
Members	Overview Members	8
	Board of Directors	10
	IF Organogram	11
	Election Committee	12
	Advisory Panels	12
	<i>Expert Panel</i>	12
	<i>Youth Group</i>	12
	<i>Volunteers</i>	12
<hr/>		
Main Achievements	Policy Statements	15
<i>Human Rights</i>	Information Resources	17
	Consultations	18
	European Commission Disability Platform	19
	Global Disability Summit	20

<i>Awareness Raising</i>	International Awareness Days	21
<hr/>		
<i>Prevention and Care</i>	Towards a WHA Draft Resolution on Safe and Effective Food Fortification	30
<hr/>		
<i>Community Building and Twinning</i>	IF Activities with Members	37
	Activities IF Advisory Groups	39
	Twinning	43
<hr/>		
<i>World Spina Bifida and Hydrocephalus Day</i>	WSBHD22 Conference ‘Elevate Your Voice’	47
	WSBHD22 Side Events	50
<hr/>		
<i>Network Development</i>	Network Development	55
<hr/>		
<i>Communications</i>	Communications at a Glance	57
<hr/>		

FOREWORD

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

Here, in this annual report 2022, the actions achieved for human rights, primary prevention, optimising management and care, raising awareness, as well as international solidarity are highlighted

The year 2022 was an active year with a special focus on advocacy towards Member States in support of a draft World Health Assembly resolution to promote safe and effective food fortification with folic acid. During the members training, the focus from local to global informed next steps as to how IF members can influence international actions through national advocacy.

Member meetings with presidents of IF member associations in the regions Africa, Americas, Asia-Pacific, and Europe were important events. Moreover, the members of the IF working groups on ageing, youth, women with SBH, and the working group on multidisciplinary care continued their activities in raising awareness on topics relevant to these groups. The members within these working groups conducted explorative studies, published reports and policy statements, organised opportunities to meet and share experiences, offered training opportunities, and participated as speakers at international events.

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

IF looks forward to unlocking potentials together with YOU and also make the next year 2023 a success!



“Each one of us can make a difference, together we make change”

- Barbara Mikulski

Cato Lie, President

Dr Sylvia Roozen, Secretary General

ABOUT IF

WHO WE ARE

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

MISSION

The mission of IF is to improve the quality of life of people with SBH and their families, and to reduce the prevalence of neural tube defects and Hydrocephalus by primary prevention through improving maternal health literacy, raising awareness, political advocacy, research, community building, and human rights education.

VISION

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

VALUES

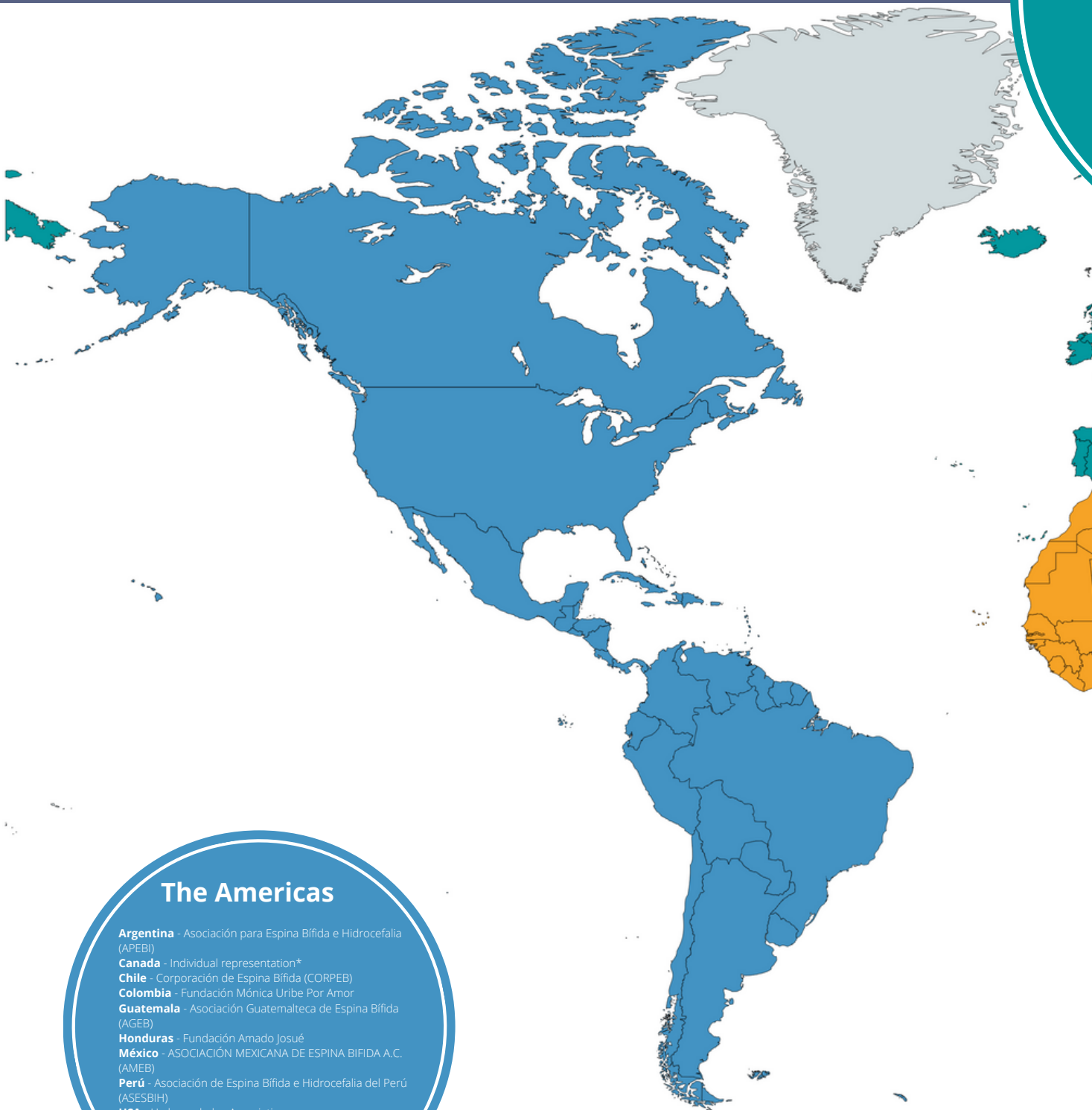
Human Rights: promotion and protection of human rights of people with SBH in accordance with the UN Convention on the Rights of Persons with Disabilities (UNCRPD) is our highest value.

Participation & Inclusiveness: the views of children and adults with SBH and their families are the leading principles in our work. We respect the regional, cultural and socio-economic specificities of our members around the world, and we promote a tailored approach to working on SBH issues.

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

Transparency & Accountability: IF works in a transparent and inclusive way, fully accountable to our members, donors and external stakeholders.

OVERVIEW MEMBERS



The Americas

- Argentina** - Asociación para Espina Bífida e Hidrocefalia (APEBI)
- Canada** - Individual representation*
- Chile** - Corporación de Espina Bífida (CORPEB)
- Colombia** - Fundación Mónica Uribe Por Amor
- Guatemala** - Asociación Guatemalteca de Espina Bífida (AGEB)
- Honduras** - Fundación Amado Josué
- México** - ASOCIACIÓN MEXICANA DE ESPINA BÍFIDA A.C. (AMEB)
- Perú** - Asociación de Espina Bífida e Hidrocefalia del Perú (ASESBIH)
- USA** - Hydrocephalus Association
- USA** - Spina Bífida Association of America (SBAA)

*In 2022, IF welcomed 12 new members.

Europe

Austria - Spina Bifida und Hydrocephalus Österreich (SB&HÖ)
Belgium - Association Spina Bifida Belge Francophone asbl (ASBBF)
Belgium - Vlaamse Vereniging voor Spina Bifida en Hydrocephalus vzw (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 - Rygmargbroksforeningen 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 section (MEOSZ)
Ireland - Spina Bifida and Hydrocephalus Ireland (SBHI)
Israel - Hydrocephalus Israel
Italy - Associazione Spina Bifida Italia (ASBI)

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

Africa

Algeria - Association des Parents et Malades Spina Bifida Béjaia
Egypt - Waad Spina Bifida Foundation
Ethiopia - HOPE-SBH Ethiopia*
Ethiopia - ReachAnother Foundation
Ghana - Rickmes Foundation
Kenya - Spina Bifida and Hydrocephalus Association Kenya (SHAK)
Malawi - Parents Association of Spina bifida and Hydrocephalus Limited (PASHL)
Morocco - Association Spina Bifida et Handicaps Associés au Maroc
Nigeria - Festus Fajemilo Foundation
Nigeria - Liron Hydrocephalus Foundation
Nigeria - Spina Bifida and Hydrocephalus Association of Nigeria
South Africa - Association for Spina Bifida and Hydrocephalus South Africa
Sudan - Spina Bifida Federal Association of Sudan
Tanzania - Association for Spina Bifida and Hydrocephalus Tanzania (ASBAHT)
Togo - Association Santé Meilleure Vie Meilleure (SM-VM)*
Uganda - Spina Bifida and Hydrocephalus Association of Uganda (SHA-U)
Uganda - Central Uganda Spina Bifida and Hydrocephalus Network (CU-SBH)
Uganda - Shared Growth Uganda (SGU)*
Uganda - TET FOUNDATION FOR SPINA BIFIDA AND HYDROCEPHALUS CHILDREN -UGANDA*
Zambia - Zambia Association for Hydrocephalus and Spina Bifida (ZAHSB)
Zimbabwe - Spina Bifida and Hydrocephalus Association of Zimbabwe
Zimbabwe - Hydrocephalus Association*

Asia-Pacific

Australia - Spina Bifida Hydrocephalus Queensland
Bangladesh - Bangladesh Hydrocephalus and Spina Bifida Welfare Trust*
Bangladesh - Bangladesh Protibandhi Kallyan Somy (BPKS)*
China - China Association of Persons with Physical Disabilities
India - Spina Bifida Foundation
Iran - Tabriz Registry of Congenital Anomalies (TRoCA)
Japan - Japan Council for Spina Bifida and Hydrocephalus
Japan - Spina Bifida Association of Japan
Kazakhstan - Spina Bifida Public Association (SBPA)
Malaysia - Spina Bifida Association Malaysia (SIBIAM)
Mongolia - Mongolian Spina Bifida Foundation "Maral Angel"
Pakistan - Individual representation
Pakistan - Pakistan Federation For Spina Bifida and Hydrocephalus
South Korea - Korea Spina Bifida Patient Association (KPSPA)
Taiwan - Taiwan Spina Bifida Support Society
Australia - Individual representations**

BOARD OF DIRECTORS



Mr Cato Lie
IF President
Norway



Mrs Victoria Sandoval
Vice President
Guatemala



Mrs Emma Suardiaz
Treasurer
Spain



**Dr Papatya Alkan
Genca**
Secretary
Turkey



Mrs Giulia Bizzotto
Italy



**Dr Aziza Mustafa
Elnaeema**
Sudan



Mr Rasmus Isaksson
Sweden



Dr František Horn
Slovakia



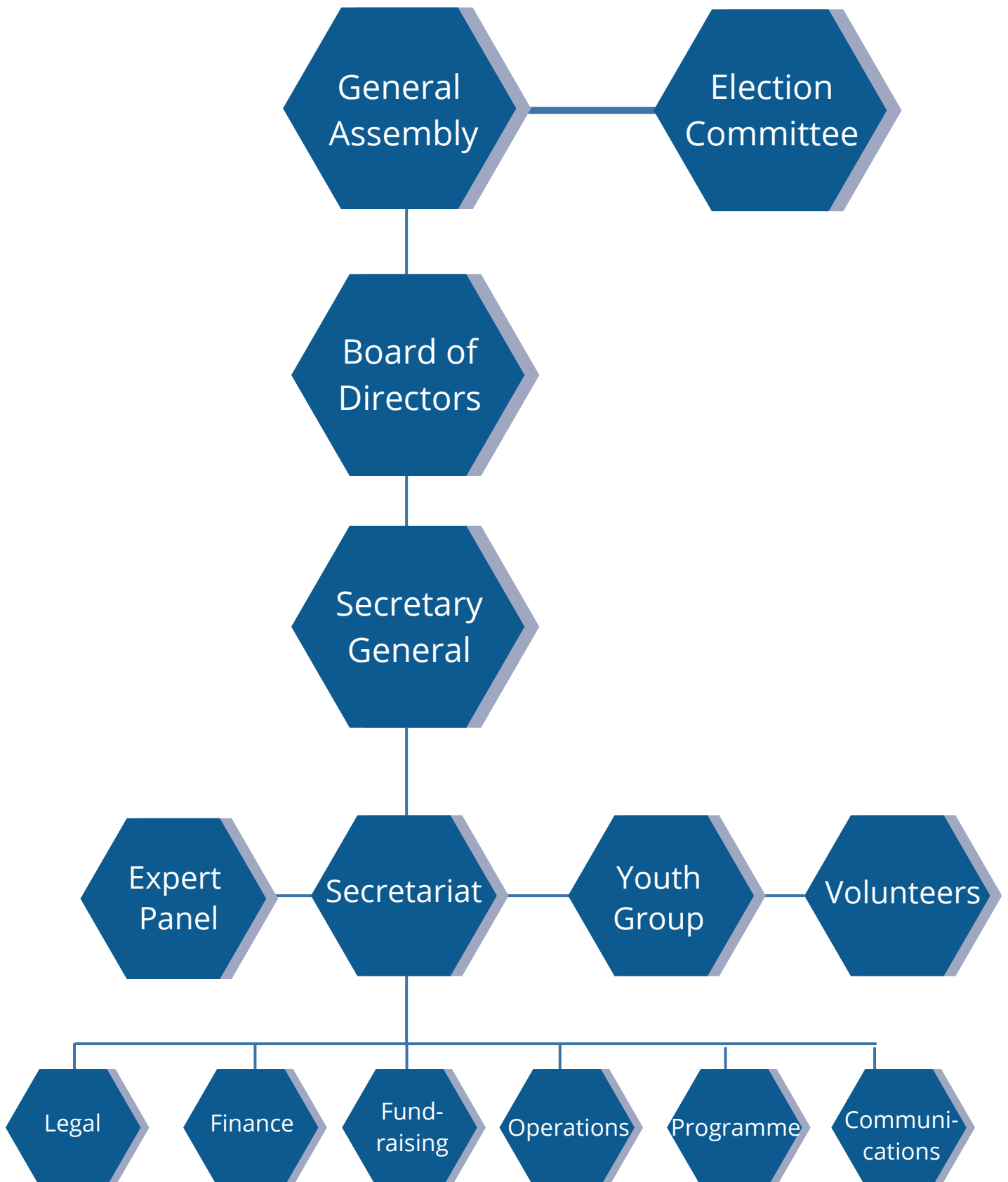
Mrs Sonia Uribe
Colombia

SECRETARY GENERAL

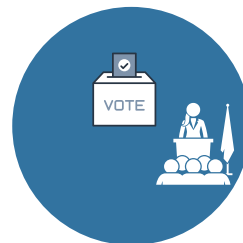


Dr Sylvia Roozen

IF ORGANOGRAM



ELECTION COMMITTEE



In 2022, the General Assembly elected the following members for the election committee:

- Dr Aziza Mustafa Elnaeema - Spina Bifida Federal Association of Sudan
- Dr František Horn - Slovenská spoločnosť pre Spina Bifida a/ alebo Hydrocefalus o.z.
- Mario Sel - Vlaamse Vereniging voor Spina Bifida en Hydrocephalus vzw (VSH)

ADVISORY PANELS

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

Expert Panel

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

Youth Group

In 2022 the youth group consisted of the following members: Cillian Dunne (chair until September 2022; Ireland), Laura Rosillo Beneyto (chair from October 2022; Spain), Ajok Proscovia (Uganda), Parth Hendre (India), Rereloluwa Adeolu (Nigeria), Mirela Bukovac (Croatia), Malik Armughan Ali (Pakistan), Rebecca Austin (Australia), Samuel Opeyemi (Nigeria), Patrícia Albertová (Slovakia).

Volunteers

In addition to these advisory groups, IF is always fortunate to work with dedicated volunteers. We are particularly grateful in the year 2022 for the support of Li Zhang Chao Yue who dedicated her time in support of IF with a video for the World Spina Bifida and Hydrocephalus Day.

MAIN ACHIEVEMENTS

Quarter 1 *Jan.-Mar.*

Community Building

through member meetings and regional members meetings

Advocacy

through the World Folic Acid Awareness Week (WFAAW) Turning Points webinar and the side event 'Advancing disability rights through multidisciplinary care' as part of the Global Disability Summit

Twinning Opportunities

through a youth only event with a Meet & Greet between youth and a motivational speaker with lived experiences. The IF Grand Round session on Incontinence Management

Partnership Strengthening

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

Awareness Raising

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

Individual Support

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

Quarter 2 *Apr.-Jun.*

Training Opportunities

for IF members, training 'From local to global: How to influence international actions through national advocacy'

Advocacy

through proposing to The Committee on the Rights of Persons with Disabilities (CRPD) to add text which emphasised the role of stigma in hindering independent living and societal inclusion of persons with disabilities

Awareness Raising

through an international awareness campaign: IF Siblings Day

Individual Support

to IF members for their national advocacy for a human rights approach to prevention

Twinning Opportunities

through IF Grand Round session on Hydrocephalus

Community Building

through regional members meetings

Partnership Strengthening

by organising a side event as part of the World Health Assembly and organising breakfast meeting with Rotary International

Publications

of the IF Annual Report, Membership Guide, conference abstracts, toolkits, and scientific article in the Lancet

Quarter 3

Jul.-Sept.

Awareness Raising

by participating in the Freedom Drive to demand an end to institutionalisation and the right to independent living

Community Building

through the IF spring webinar 'Learning from Experience: Strategic Advocacy for Primary Prevention'; and regional member meetings

Advocacy

through the youth only meeting as part of the International Youth Day entitled 'Independent Living in Your Eyes'

Training Opportunity

through the IF training: 'Human Rights and Advocacy Training - Accessibility in Focus' especially aimed at youth

Publications

of the IF Statement on Independent Living; IF Statement on 'A Call for a Global Action to Reduce the Prevalence of Neural Tube Defects Worldwide'; the 29th International Conference on Spina Bifida and Hydrocephalus Programme Book; Report 'Ageing With Spina Bifida and Hydrocephalus: An Overview of Best Practices Around the World'; infographics and toolkits supporting these publications

Twinning

Through organising the four day long 29th International Conference on Spina Bifida and Hydrocephalus - Diverse Needs, Same Rights including a pre-conference workshop on the topic of independent living

Quarter 4

Oct.-Dec.

International Solidarity

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

Community Building

through the IF autumn webinar which consisted of four regional meetings organised by IF in collaboration with member association ASBI Italy

Awareness Raising

through international awareness days: International Day for Older Persons; World Mental Health Day; International and European Days for Persons with Disabilities

Twinning

through the webinar 'Neural Tube Defects in sub-Saharan Africa'; international conference on neural tube defects

HUMAN RIGHTS

POLICY STATEMENTS

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

IF Statement: A Call for a Global Action to Reduce the Prevalence of Neural Tube Defects Worldwide

IF takes a human rights based approach to primary prevention and healthcare policies. With a new statement published in September 2022, IF called for urgent action demanding universal mandatory food fortification with vitamin B9 (folic acid) to reduce the risk of Spina Bifida, Anencephaly, or Encephalocele, also called Neural Tube Defects. IF has been at the forefront of the advocacy for universal mandatory food fortification for the primary prevention of Neural Tube Defects (NTDs) including Spina Bifida. As a result the number of countries with policies of food fortification with vitamin B9 have increased. However, progress on the global level is insufficient.

In this statement IF outlined:

- What NTDs are;
- How NTDs are affected by the social determinants of health;
- What food fortification is and how it reduces the prevalence of NTDS;
- The economic benefits of food fortification;
- The stakeholders needed to be involved to make mandatory fortification of staple foods with folic acid a global reality;
- The primary prevention of NTDs in the context of disability rights;
- The need for an effective rights-based approach for the primary prevention of Spina Bifida and other NTDs;
- IF's recommendations on achieving a global reduction in the prevalence of NTDs through food fortification.

IF Statement on Independent Living

The IF Statement on Independent Living was published in December 2022 and drafted following a successful year of activities on the topic spearheaded by the IF International Youth Group SBH. The statement defined independent living in line with article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), general comment no 5 on article 19 - the right to live independently and be included in the community and the recently published guidelines on deinstitutionalisation, including in emergencies adopted by the Committee on the Rights of Persons with Disabilities (CRPD) in September 2022.

The statement outlines how independent living intersects with other policy areas including the right to health, employment, education and more. As well as how important changing societal perceptions of SBH and disability is to advance independent living. While the statement did take a broad perspective on independent living, focusing on the right to make your own choices and be supported in those choices and exploring the enabling factors and barriers, both visible and invisible, to realise that right. The important issue of deinstitutionalisation was also addressed in the statement. The statement concludes with a list of recommendations to International organisations and other stakeholders on the international and regional level including the EU, as well as recommendations for policy makers on the national and local level.



INTERNATIONAL FEDERATION
FOR SPINA BIFIDA
AND HYDROCEPHALUS

IF Statement on Independent Living


For the International Federation for Spina Bifida and Hydrocephalus (IF) representation of the entire global Spina Bifida and Hydrocephalus (SBH) community is central to the work of the federation. In line with that value, IF established the IF International Youth Group to facilitate and support the involvement of youth with SBH in advocacy. Each year the IF International Youth Group chooses a topic which they deem to be of the highest priority for young people with SBH. This statement focuses on the important topic of independent living.

In this statement IF outlines how independent living is enshrined in international human rights law, its interpretation and implementation and how that relates to the main concerns of the global SBH community, as identified by the IF the International Youth Group. Concluding with recommendations to policy makers and all those involved in supporting people with SBH on how to advance the right to independent living for the SBH community worldwide.

Article 19 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) establishes the right to live independently and being included in the community. Within it, independent living is defined as not just as an absence of a large institution, but as the right and ability to make choices equal to others, to have the opportunity to choose your own place of residence and with whom you live with. To have access to a wide range of community support services and not to be obliged to live in a particular living arrangement. Misconceptions and confusions about the definition of independent living and how that relates to policy changes on the national level, in particular for the process of deinstitutionalisation of persons with disabilities, are all too common. In 2017, to aid State Parties to the UNCRPD in interpreting and implementing article 19, the Committee on the Rights of Persons with Disabilities (CRPD) published *General Comment No 5 on Article 19 - The Right to Live Independently and be Included in the Community*.⁽¹⁾


In General Comment No 5 the CRPD emphasised how article 19 of the UNCRPD must be interpreted in context of the convention as a whole. In particular, State Parties should look towards the general principles established in article 3 of the UNCRPD which include respect for the individual's inherent dignity, autonomy and independence. As well as inclusion and effective participation in society. General Comment No 5 emphasises that independent living can only be fully realised if all economic, civil, social and cultural rights enshrined in the Convention are fulfilled.

The interconnected nature of independent living for persons with Spina Bifida and/or Hydrocephalus to a plethora of other policy areas are revealed throughout IF's work on variety of issues such as access to integrated multidisciplinary health care,⁽²⁾ ageing with SBH,⁽³⁾ mental, physical and sexual health.⁽⁴⁾



INTERNATIONAL FEDERATION
FOR SPINA BIFIDA
AND HYDROCEPHALUS

A call for global action to reduce the prevalence of Neural Tube Defects worldwide



The International Federation for Spina Bifida and Hydrocephalus (IF) is calling for urgent action demanding universal mandatory food fortification with vitamin B9 (folic acid) to reduce the risk of Spina Bifida, Anencephaly or Encephalocele, also called Neural Tube Defects (NTDs).

Decades of evidence have demonstrated that mandatory fortification of staple foods with Vitamin B9 is the most effective and cost-efficient method to reduce the prevalence of NTDs.

Vitamin B9 is a micro-nutrient. Food fortification is a process where micro-nutrients are added to commonly consumed foods to improve nutritional quality.

Maternal intake of vitamin B9 before and during pregnancy reduces the risk of NTDs because vitamin B9 is essential for a healthy periconceptional period, being the 14 weeks before and 10 weeks after conception.

IF calls on all relevant stakeholders to support a global action that includes the following recommendations:

- To develop and implement mandatory fortification programs of vitamin B9 in staple foods for the prevention of NTDs
●
- To make mandatory fortification of staple foods with vitamin B9 a global priority
●
- To raise awareness of NTDs, combat stigma associated with them and of effective rights-based prevention strategies which respect the dignity and rights of persons with disabilities among all relevant stakeholders including government officials, health professionals, civil society and the public
●
- To ensure that mandatory fortification programs adhere to international standards and guidelines
●
- To promote and strengthen primary prevention of NTDs through food fortification by involving all relevant actors. In particular, ensuring that the development of the policies are done in accordance with article 4(3) of the UN Convention on the Rights of Persons with Disabilities by consulting persons with disabilities, including persons with NTDs, and their representative organisations in the development of policies relevant to them, including policies for the primary prevention of NTDs
●

CONTACT DETAILS
The International Federation for Spina Bifida and Hydrocephalus
Cellebroersstraat 16,
1000 Brussels (Belgium)
+32 (0) 471 84 41 54
info@ifglobal.org
www.ifglobal.org

Disclaimer: Co-funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the European Commission. Neither the European Union nor the granting authority can be held responsible for them.

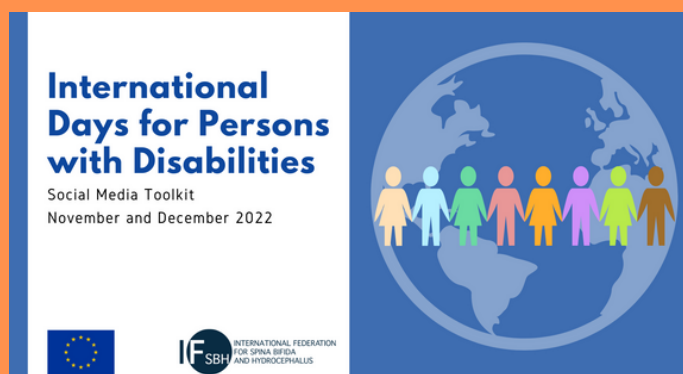
Co-funded by the European Union

INFORMATION RESOURCES

IF created information packages and resources to provide IF members further support in visibility activities on EU national and international policies. This year the information package was particularly created in support of the campaign for a World Health Assembly (WHA) resolution on food fortification with folic acid.

The following three resources were published in 2022:

- **IF Information Package on Global Advocacy for Prevention through Food Fortification:** IF has been working with an international coalition of neurosurgeons to raise awareness of Folic Acid Fortification with the WHO with the goal of having the WHA adopt a resolution on Folic Acid Fortification. In this information package, IF highlighted the importance of mandatory folic acid fortification of staple foods to prevent Spina Bifida and Anencephaly. Urging the WHO to support a resolution on mandatory folic acid fortification at the World Health Assembly;
- **Steps for an Advocacy Campaign:** The toolkit addresses the creation, implementation, and evaluation of advocacy campaigns in 9 steps;
- **IF Toolkit as Part of Raising Awareness for the International Days of Persons with Disabilities (IDPD):** On December 3 2022 IF advocated for the rights of persons with disabilities during IDPD. The United Nations General Assembly declared this day in 1992 (by resolution 47/3) with the goal to promote the rights and well-being of people with disabilities in all aspects of society and development, as well as to raise awareness about their position in political, social, economic, and cultural life.



EUROPEAN COMMISSION DISABILITY PLATFORM

Since the inauguration of IF as a member of the European Commission Disability Platform, IF remained an active participant within the European Commission Disability Platform in 2022, advocating on key issues within the EU, contributing to the creation of the yearly work programme and participation in meetings. Furthermore, IF became an active member for the subgroup on independent living.

The objectives of the Disability Platform are:

- To facilitate cooperation between the European Commission and 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.



GLOBAL DISABILITY SUMMIT

IF organised a side event as part of the Global Disability Summit (GDS) and was active on social media to raise awareness about the rights and needs of persons with SBH. The highlight of the GDS for IF was the federation's official GDS side event. The event was titled 'Advancing disability rights through multidisciplinary care' and explored healthcare systems and inclusive health for persons with SBH from the perspective of disability rights. The event had a diverse set of speakers to address the topic from different viewpoints. At the centre of the discussions were persons with SBH who discussed the personal experiences of the SBH community, the different barriers to multidisciplinary care and the work of IF and its member associations.

IF invited an international panel of speakers who are all leading by example. The IF President opened the meeting and welcomed all speakers, delegates and participants. The first speaker, Dr Xanthe Hunt (World Health Organization (WHO) representative) shared current contributions by WHO in collaboration with UNICEF to accelerate Inclusive Health for All. Important pillars of work were shared such as accessibility and overcoming stigma and the need for coordinated actions and mainstreaming these.



Thereafter, MEP Stelios Kypouropoulos gave an inspiring speech on personal experiences on the advocacy of disability rights in health policy to accelerate Inclusive Health for All. The chair of the IF working group on ageing with SBH, Dr Kevin O'Donnell, provided perspectives on what person-centred care means for a person with Spina Bifida. Moreover, the recent work by the ageing working group was used as an example. The chair of the Latin-American Network SBH (RELAEHBI), former president of IF member association in Argentina APEBI, and former IF board member, Elena Zappoli, provided an overview of excellent activities going on in Latin American countries. Elena showed us how strong a network can be in building inclusive societies also with respect to inclusive health.

Moreover, another active IF member Anđela Radovanović, programme manager at the Association of Youth with Disabilities of Montenegro, shared insights into an inclusive policy model of health. She strongly recommended youth to become actively involved with their national associations to advocate for a more inclusive policy model of health.

In conclusion, Dr Sylvia Roozen IF Secretary General concluded there is a need for more leadership from persons with disabilities. Whereby the speakers of this side event have truly shown to lead by example. The human rights approach of this event was further entrenched by the perspective of persons with disabilities such as SBH as well as speakers who all are dedicated to making change happen in policy and health services.

AWARENESS RAISING

All IF's activities are rooted in the ultimate mission to advance and protect the rights of individuals with SBH. Throughout the year of 2022, IF organised various activities to address the objective of raising awareness on the rights of persons with SBH. Activities included participating in meetings and events, contributions to consultations, and publications of statements. In particular, the focus was on the priorities indicated by IF members for themes such as independent living, multidisciplinary care, and prevention.

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

The overall objectives to raise awareness include:

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

#YouthSBHandIndependentLiving

REBECCA AUSTIN, AUSTRALIA

I am still really struggling from a mental health point, but I know that living by myself gives me the most comfort and freedom to do whatever I need to do to get through each day, without having to worry what other people are thinking of me.

Happy Youth INTERNATIONAL DAY

#InternationalYouthDay
#YouthSBH
#YouthSBHandIndependentLiving
#YouthSBHVoice

IF - International Federation of Spinal Cord Injury Associations
EUROPEAN COMMISSION

#YouthSBHandIndependentLiving

Parth Hendre, India

It is extremely important for individuals with SBH to focus on how to make themselves capable of living as independently as possible. It also helps to instill a sense of pride and dignity and develops one's confidence levels to go through in life.

Happy Youth INTERNATIONAL DAY

#InternationalYouthDay
#YouthSBH
#YouthSBHandIndependentLiving
#YouthSBHVoice

IF - International Federation of Spinal Cord Injury Associations
EUROPEAN COMMISSION

INTERNATIONAL AWARENESS DAYS

In 2022, IF continued to raise awareness on the rights of individuals with SBH and the UNCRPD among policy makers, relevant stakeholders, and international organisations. IF held awareness campaigns for several international awareness events: the World Folic Acid Awareness Week; Rare Disease Day; World Birth Defects Day; International Women's Day; World Health Day; IF's Siblings Day; International Youth Day; World Spina Bifida and Hydrocephalus Day; International Day for Older Persons; World Mental Health Day; International/European Day of Persons with Disabilities, and the World Toilet Day. For seven of these international awareness events IF developed social media toolkits to support members and partners in their advocacy efforts. These toolkits were developed for:

- World Folic Acid Awareness Week
- World Birth Defects Day
- International Women's Day
- IF's Siblings Day
- International Youth Day
- World Spina Bifida and Hydrocephalus Day
- International/European Day of Persons with Disabilities



World Folic Acid Awareness Week

Each year in January IF together with its members and partners celebrate the World Folic Acid Awareness Week. IF is driven by its mission to decrease the birth prevalence of Spina Bifida and Hydrocephalus through primary prevention measures and to improve the quality of life for those living with these disabilities. To keep the momentum going in 2022, IF wanted to take the opportunity to transform the way the world tackles the global challenge of malnutrition and prevention of Neural Tube Defects. For this occasion, IF organised the webinar 'World Folic Acid Awareness and Turning Points' including speakers from all over the world sharing their perspectives on how we can build a smarter, stronger, and healthier future for all.

As a first speaker and panellist, Dr Godfrey Oakley (Director of the Center for Spina Bifida Prevention, Emory University, Atlanta) highlighted the opportunity to improve the health of millions of children today and generations to come. Dr Oakley shared several types of Spina Bifida:

- Spina Bifida F caused by folate deficiency;
- Spina Bifida V cause by the drug valproic acid;
- Spina Bifida D caused by maternal insulin dependent diabetes mellitus;
- Spina Bifida X which cause is unknown.

"Each stage of pregnancy should be a positive experience, ensuring women and their babies reach their full potential for health and well-being."
- WHO

Planned pregnancies can have positive outcomes on both the health of the mother and the baby.

IF SBH INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

World Folic Acid Awareness Week

From January 3rd to 9th 2022
Social Media Toolkit



The second panellist, Victoria Sandoval (Trustee, Asociación Guatemalteca de Espina Bífida (AGEB), Guatemala) shared her perspective on prevention from awareness raising campaigns in Guatemala. She emphasised the fact that pregnancies cannot always be planned, which makes providing folic acid to all women of reproductive age on a daily basis even more important. Together with her association in Guatemala, a multisectoral approach is applied to raise further awareness.

Thereafter Scott Montgomery (Director of the Food Fortification Initiative (FFI); implementing partner Smarter Futures) shared the importance of public-private-civic partnerships such as Smarter Futures.

Food fortification is one of the most powerful tools we have to tackle malnutrition due to its distinct combination of qualities including scalability, sustainability, and cost-effectiveness. Smarter Futures and FFI are committed to ensuring all people can consume diets rich in folic acid and to preventing neural tube birth defects. For this, there are several key actors such as millers—without millers, there is no flour fortification. Governments are also key—they enable fortification through a supportive regulatory environment. They aim to build capacity in these networks and provide technical support and training.

Kate Steele (CEO of Spina Bifida Hydrocephalus Information Networking Equality (SHINE) in the UK) spoke about a 30-year long journey in making fortification a priority in the UK. Since 2017, SHINE has tremendously worked on folic acid awareness and reached the decision-makers to unlock the prevention of Spina Bifida through mandatory fortification. In 2018, SHINE reached the Parliament with their 'Fight for Fortification' campaign which later led to a public consultation in June 2019. The consultation closed in September 2021 with the introduction of mandatory fortification of flour with folic acid in the UK.

Several lessons learned were shared, such as the importance of involvement of persons with Spina Bifida who made the campaigns more impactful with their voices and experiences alongside evidence and scientific-based information, which is essential. Partnership is key in such a campaign to be heard. Contacts at government level are a strong ally to bring the campaign to the governments' agenda. The millers and flours industries were also important players. While leading this campaign, Kate Steele also mentioned the importance of understanding the point of the opposition to be prepared to respond. Last but not least, Kate drew attention to planning and preparing such a campaign. She concluded her speech with the following words: "Know your goal, plan and prepare, work with others and believe!"

JOIN THE WFAAW 2022 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.



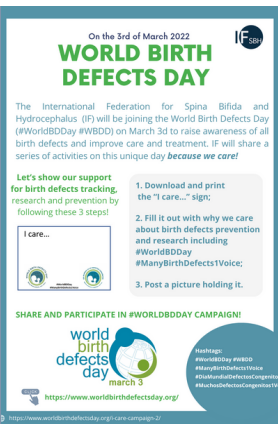
The fifth panellist and speaker was Dr Jeffrey Blount (Paediatric neurosurgeon, Chair of GAPSBi-F consortium). Dr Jeffrey Blount emphasised the importance of science-based advocacy and the widespread fortification such as salt fortified with folic acid. Neurosurgery is part of each life stage ('across the spectrum of life') of persons with Spina Bifida. Neurosurgical intervention is often the first medical treatment the child needs by closing the back. Dr Jeffrey Blount pointed out that multidisciplinary care is essential as persons with Spina Bifida go to adulthood where a multidisciplinary approach is needed. As chair of the GAPSBi-F consortium, Dr Blount shared that neurosurgeons are strong advocates to connect with policy-makers and make fortification. Together with the partners of GAPSBi-F, Dr Blount looks forward in making significant steps forward.

Hereafter, Sylvia Thawani (National Coordinator at PASHL, Malawi) shared PASHL's work in Malawi. Sylvia emphasised that fortification and Spina Bifida are not well understood by citizens. PASHL advocates for better access to folic acid prior to pregnancy and in particular for women of childbearing age. As an active parent organisation, the members of PASHL advocate and raise awareness for large-scale fortification of wheat and maize flour. Sylvia Thawani outlined the importance of encouraging persons with Spina Bifida to advocate for themselves by sharing their experiences and raising awareness. As an example, the youth in Malawi do this through movies and digital means. For the year 2022, PASHL focusses on strengthening its existing network and position to influence decision-makers on governmental level.

The last panellist Dr Santosh Karmarkar (Founder and Trustee of Spina Bifida Foundation India) shared his perspective from the progress on fortification in India. Similar to earlier speakers, Dr Karmarkar shared the need for improved and widely available information on Spina Bifida and aspects of prevention. Previous year Dr Karmarkar initiated the India Birth Defects Task Force, which is a network of experts, individuals (including parents and members) and organisations. This Task Force is working on launching a national awareness-raising campaign and is currently engaged in ensuring proper fortification standards in India. Dr Karmarkar also encouraged countries to constitute task forces with international experts on board and lobbying with governments.



World Birth Defects Day



On March 3 2022, IF celebrated the 7th edition of the World Birth Defects Day (WBDD) with the theme 'Many birth defects, one voice' as this day recognises our collective voice in raising awareness for different types of birth defects. During the WBDD IF joint international partners in its advocacy for prevention, improved care and knowledge of causes of birth defects.

For this day, IF created a toolkit which included key messages, resources, hashtags and infographics to be used on social media to raise awareness of birth defects. Through the toolkit IF members and partners shared key information through their social media channels with friends, colleagues and families during this important day.

International Siblings Day

IF celebrated the International Siblings Day on April 10 2022. For the Siblings Day IF invited every individual with a sibling with SBH to share the activities they like to do with their siblings. IF members particularly posted many pictures and videos online of siblings celebrating this important day.



"I want to celebrate my brother in this picture for not giving up on me, for giving all he can afford to meet my hard medical bills.. Sam if I could give you the world , I could...but just know your days on earth are many for having my back...on this long but difficult journey of living with spina bifida and hydrocephalus I gain my strength from you..."

Ephrance Nadongo
(Uganda)



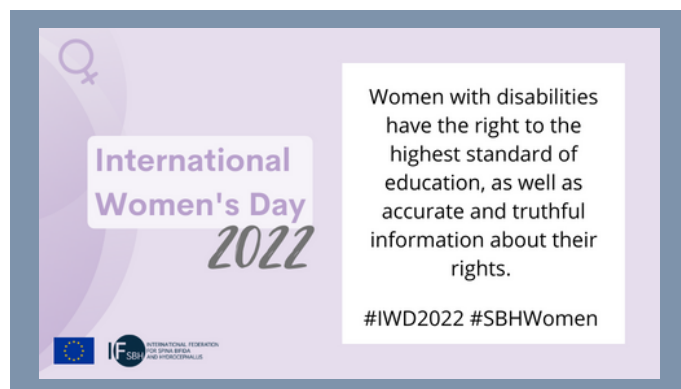
"Que seas parte de mi camino es el regalo más importante que la vida me pudo regalar"

Daiana Nacim
(APEBI Argentina)



International Women's Day

Each year, IF celebrates the International Women's Day on March 8 2022 together with our global community and IF Women Focus Group Discussions. Maternal health and empowering women with SBH has a strong focus for IF. IF does this also through several partnerships. As such, IF is an advisor to the UN Women and project holder of the unique Smarter Futures partnership.



Together with the members of the IF international working group on sexual health, IF facilitated meaningful discussions between women with Spina Bifida and Hydrocephalus through focus group discussions on topics such as equality, motherhood and sexuality. The theme of 2022 for the International Women's Day was 'Gender equality today for a sustainable future tomorrow'. The theme recognised the contribution of women and girls around the world, who are leading the charge on climate change adaptation, mitigation, and response, to build a more sustainable future for all. The theme also aligned with the priority theme for the upcoming 66th Commission on the Status of Women (CSW66): 'Achieving gender equality and the empowerment of all women and girls in the context of climate change, environmental and disaster risk reduction policies and programmes'.

March 8th 2022
International Women's Day
Social Media Campaign

Get ready for the 66th session of the Commission on the Status of Women

The sixty-sixth session of the Commission on the Status of Women will take place from 14 to 25 March 2022. Representatives of Member States, UN entities, and ECOSOC-accredited non-governmental organizations (NGOs) from all regions of the world are invited to contribute to the session.

Themes

- **Priority theme:** Achieving gender equality and the empowerment of all women and girls in the context of climate change, environmental and disaster risk reduction policies and programmes;
- **Review theme:** Women's economic empowerment in the changing world of work (agreed conclusions of the sixty-first session)

For more information, please visit the UN website page [here](#).

International Youth Day

On August 12 2022, IF celebrated the International Youth Day. This was an opportunity for young people to draw attention to youth issues around the world and the IF International Youth Group SBH wanted to address several issues related to the current theme of the year, independent living. On this day, the youth group created a toolkit which included information on how the youth group will celebrate the International Youth Day, quotes, relevant hashtags, various materials to download, and an invitation for the SBH youth community to join them. The IF International Youth Group SBH either shared a story of their independent living and/or recorded a video telling what independent living means to them, their current situation, their thoughts, their issues and lessons learned about independent living. By doing this, the youth group aimed to raise the awareness of not only youth but everyone with SBH about living independently.

"At age of 17 I did my driving licence so since that I drive I would say every day [...] I am able to take care of the household, cook, wash dishes, wash clothes and I also study at university. It is not easy but I can do it" - **Patricia Albertová**

"I realise not everywhere is as lucky as Australia in the system of living and support, but I'm sure there are ways we can all increase our independence, if we just look for it together. Make sure you get the support you need! That's still living independently" - **Rebecca Austin**



International and European Days of Persons with Disabilities

On December 3rd, IF celebrated the International Day of Persons with Disabilities (IDPD). The United Nations General Assembly declared this day in 1992 (by resolution 47/3) with the goal to promote the rights and well-being of people with disabilities in all aspects of society and development, as well as to raise awareness about their position in political, social, economic, and cultural life. Additionally, IF celebrated the European Day of Persons with Disabilities on 24 – 25 November by joining the annual conference organised by the European Commission in partnership with European Disability Forum in Brussels, Belgium. This two day long conference marked the International Day of Persons with Disabilities. The focus of the 2022 agenda was on young people with disabilities since 2022 was the European Year of Youth. In addition to the conference other topics, such as what international instruments are there to help make the ambition for the Union of Equality a reality, were explored. Furthermore, there was a focus on addressing violence in the context of disability rights. This included the rights of persons with disabilities in times of war or conflict and other forms of violence that persons with disabilities may face in their lives.

The European Day of Persons with Disabilities Conference in Brussels

November 24 2022



On the picture: Slaveya Kostadinova (IF member Bulgaria), Emma Suardiaz (IF Board Member), Cato Lie (IF President), Dr Sylvia Roozen (IF Secretary General), Hildur Önnudóttir (IF Policy Officer), Shantal Martis (IF Project Officer)



PREVENTION & CARE

TOWARDS A WHA DRAFT RESOLUTION ON SAFE AND EFFECTIVE FOOD FORTIFICATION

IF has been a vocal proponent for large scale food fortification with folic acid for decades and as a part of that advocacy has been working with partners for the past year to bring a strong resolution on food fortification for reducing the prevalence of Spina Bifida and other Neural Tube Defects to the World Health Organization. This was especially apparent in previous years through IF's public-private-civic partnership, called Smarter Futures.

To accelerate our efforts IF urges the World Health Assembly and its Member States to support a draft resolution on mandatory folic acid fortification. In 2022, the activities below were organised to give further awareness to this call to action.

ADVOCACY TOWARDS MEMBERS STATES

Awareness and advocacy for the primary prevention of NTDs risks stigmatising people with NTDs including Spina Bifida and their families if not designed and implemented from a rights-based perspective. Successful primary prevention policies must look towards article 8(b) UNCRPD and seek to “To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life”. Policies for the primary prevention of NTDs including Spina Bifida must be designed with the input of the SBH community and implemented in a way which does not use stigmatising language or images nor contradicts or hinders the full realisation of the rights of people with NTDs such as Spina Bifida as outlined in the UNCRPD.



Local Spina Bifida and Hydrocephalus Associations possess connections and expertise on the national level which are essential for the advancement of policies for the primary prevention of NTDs. SBH associations connect abstract international level guidelines and recommendations to personal experiences with a variety of important stakeholders, from policy makers to the private sector, can connect with. While also doing so in ways which adhere to the current international norms in regards to public health interventions and disability rights.

What IF is looking for in advocacy on the international level is the ability to shape the discourse and strengthen the legitimacy of our policy asks. In the context of primary prevention that discourse is twofold: (i) Political: for the international community to identify the primary prevention for the reduction of the prevalence and reoccurrence of Neural Tube Defects as a global priority; (ii) Technical: to establish the methods in how this needs to be addressed. i.e.

evidence based policy making, establishing mandatory fortification of staple foods with vitamin B9/folic acid as the primary policy for reducing the prevalence and reoccurrence of NTDs, with the use of supplements and consumption of foods rich in vitamin B9 as complementary actions. International actions require national advocacy as they are interconnected. It is imperative to have the push for change come from the national level and the voices of the SBH community be loud and visible in these actions, thereby advancing the rights and needs of persons with SBH. For this, IF and IF members have been a vocal proponent for large scale food fortification with folic acid for decades and as a part of that advocacy has been working with partners for the past year to bring a strong resolution on food fortification for reducing the prevalence of Spina Bifida and other Neural Tube Defects to the WHA.

INSTALMENT OF THE IF ADVOCACY COMMITTEE

The IF Advocacy Committee was established in 2022 in follow up to IF members training earlier in the year. The IF Advocacy Committee was launched at an IF members meeting. The Committee met on a regular basis where its members discussed the successes and challenges that they have had in their own countries and discussed how IF can support the wider IF membership to participate in the advocacy for a World Health Assembly (WHA) resolution on food fortification for the prevention of Neural Tube Defects. Several actions were set by the committee including a strategy to reach national policy makers and stakeholders including the development of a wide range of resources.

WORLD FOLIC ACID AWARENESS WEEK

During the first week of the year 2022, IF together with its global community celebrates the World Folic Acid Awareness Week. Food fortification and folic acid supplementations are essential tools for prevention, especially in times of a pandemic. During this week, the federation takes the opportunity to transform the way the world tackles the global challenge of malnutrition and prevention of Neural Tube Defects.

The webinar gathered a panel of experts with a proven track record in global leadership for the prevention of NTDs. During this webinar, all panellists including Dr Godfrey Oakley, Victoria Sandoval, Scott Montgomery, Kate Steele, Dr Jeffrey Blount, Sylvia Thawani, and Dr Santosh Karmarkar, shared their unique experiences, visions and wishes for the upcoming time. Several strong messages were shared to reach significant Turning Points in NTD prevention (what is needed, for whom, and how, and the need for longtime commitment to make change happen together). The webinar gave insights in how countries can create political will, but also about building networks on each level within the society to mainstream our message that healthy pregnancies start with a healthy lifestyle including balanced diet.

Take Part in the WFAAW 2022 Social Media Awareness Raising Campaign

Join IF during the WFAAW 2022 to raise awareness on the important topic of Spina Bifida and Hydrocephalus prevention.

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

Prevention is a combined effort.



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



THE LANCET GLOBAL HEALTH PUBLICATION

On May 23 2022 the joint publication titled 'Preventing birth defects, saving lives, and promoting health equity: an urgent call to action for universal mandatory food fortification with folic acid' was published in The Lancet Global Health. The authors include IF Secretary General Dr Roozen alongside a broad coalition of leading global experts. The publication highlights that despite the fact that the role of folic acid in reducing the prevalence of NTDs such as Spina Bifida has been known for over three decades, many countries have failed to implement mandatory food fortification with folic acid. The publication makes an urgent call for global action, urging the World Health Assembly to pass a resolution for universal mandatory folic acid fortification. In this way, IF calls on WHO Member States, the European Union and all other stakeholders in the public, private and civic sectors to join the federation in this campaign.



WHA75 SIDE EVENT

On the occasion of the Seventy-fifth World Health Assembly (WHA75) in Geneva, Switzerland, IF together with GAPBiF and G4 Alliance organised the WHA75 side event 'Folic Acid Fortification to Prevent Spina Bifida' on May 24 in Geneva, Switzerland.

Dr Gail Rosseau (Clinical Professor, Moderator, GAPSBiF) opened the meeting and welcomed all speakers, delegates and participants. The first speaker, Dr Nebiyat Tesfaye (SBH Program Coordinator, St. Peter's Specialized Hospital, Federal Democratic Republic of Ethiopia Ministry of Health) gave an inspiring speech from the perspective of a person with spina bifida. Thereafter, Dr Rick Boop (Professor, St Jude Children's Research Hospital) shared updates on treatments, impact and consequences of spina bifida and anencephaly. Dr Vijaya Kancherla (Assistant Professor, Emory University Rollins School of Public Health) provided epidemiology of spina bifida and anencephaly. Besides wheat and maize fortification with folic acid, Dr Kancherla highlighted the possible prevention of spina bifida with salt fortification and called for WHA resolution for folic acid fortification. Additionally, Dr Helena Pachón (Research Professor, Food Fortification Initiative) shared research results showing that folic acid fortification is the safe and effective action towards Spina Bifida prevention.

Dr Sylvia Roozen (Secretary General, International Federation for Spina Bifida and Hydrocephalus) highlighted the importance of public-private-civil society partnership for science-based advocacy with the example of Smarter Future, a partnership between flour millers, governments, vitamin and mineral suppliers, international organisations, and academic institutions to make fortification of wheat and maize flour a reality in Africa. Dr Germán Escobar (Vice-Minister of Health, Republic of Colombia) shared the process and possible challenges of the WHA Resolution. He also showed a strong commitment to take the lead on the campaign for a global action on preventable birth defects with folic acid fortification.

The side event gave insights into how folic acid fortification will bring the world closer to the goal of reducing child mortality and achieving health equity. Most importantly, this side event is the evidence of the strong partnership and contribution of IF, GAPSBiF, G4 Alliance and the support of the Vice-Minister of Health of the Republic of Colombia and all other partners. It is all about international solidarity and what we can do together to fight for the same objectives.

Folic acid (vitamin B9) prevents spina bifida and anencephaly F

23% Only about 60 countries have mandatory folic acid fortification policy for wheat flour, maize flour, and/or rice. This is preventing just 23% of all folic acid-preventable spina bifida and anencephaly worldwide.

Equators with effective mandatory folic acid fortification policies for wheat flour, maize flour, and/or rice

Food fortification with folic acid is...

- Effective everywhere
- Safe for everyone

Food fortification with folic acid is highly cost saving

There is a need for a World Health Assembly (WHA) resolution supporting large-scale food fortification with folic acid.

A WHA resolution will accelerate fortification policy and help countries reach their 2030 Sustainable Development Goals on child mortality and health equity.

Be a champion for folic acid fortification

- Saves lives
- Saves money
- Saves resources

A World Health Assembly Resolution: Folic Acid Fortification to Prevent Spina Bifida

WHA75 SIDE EVENT

Geneva, May 24th
6:00 PM - 9:00 PM
Hilton Geneva Hotel & Conference Centre
Route François-Peyrot 34
Geneva, 1218, Switzerland

WHA75 SIDE EVENT: FOLIC ACID FORTIFICATION TO PREVENT SPINA BIFIDA

Dr Germán Escobar, Vice Minister of Health of Colombia

A Public-Private-Civic Partnership

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

MEMBERS TRAINING

The IF members training 'From local to global – how to influence international actions through national advocacy' taking place on May 6 2022 provided an overview of key concepts and processes of international organisations. The role of civil society in shaping the activities of international organisations and how campaigns for actions are designed and implemented. Most importantly, the training demonstrated how national SBH associations can make a change at the international level with concrete examples of best practice. Mandatory fortification of staple foods with folic acid was the focus theme used to demonstrate the practical applications of this type of advocacy as well as to provide inspiration for IF members to participate in the campaign for a WHO resolution on mandatory fortification of staple foods with folic acid. At the end of the training, all participants gathered for discussions on how to identify key issues in specific countries and explore practical strategies to advocate effectively in their regions.



WEBINAR

On July 15, 2022, IF held an experience exchange and sharing webinar named 'IF webinar Learning from Experience: Strategic Advocacy for Primary Prevention'. The webinar was an experience exchange and twinning opportunity for all IF members, in which representatives from Africa, Asia-Pacific, Latin-America and Europe who have advanced their national advocacy for primary prevention shared their key element of success, the process, lessons learned and advice for all participants.

The IF Webinar Learning from Experience: Strategic Advocacy for Primary Prevention was in particular successful as it provided members with opportunities to learn from peers, to take away strategies and lessons for effective advocacy work and to be inspired to take further steps in national, European and international advocacy activities. From this webinar, it is highlighted that capacity building activities in the form of experience exchange and sharing should be repeated since participants could feel more relatable and motivated to learn from success stories and best practices from other IF members. Moreover, this twinning opportunity can also strengthen the network of the SBH community. IF will, therefore, continue to facilitate such opportunities.

WEBINAR
LEARNING FROM EXPERIENCE
Strategic Advocacy for Primary Prevention

Are you interested in Policy and Advocacy? You are invited!
Join IF on July 15th 2022 to learn from worldwide IF members who have advanced their national advocacy!

OUR PANELISTS

Panelist	Region	Role
Kate Steele	EUROPE	CEO Spina Bifida Hydrocephalus Information Networking Equality (SHINE)
Joline Owinga	AFRICA	National Coordinator Spina Bifida and Hydrocephalus Association Kenya (SHAK)
Lyll Thurston	ASIA - PACIFIC	Former National President New Zealand CCS (CCS Disability Action), Advocate and lobbyist for folic acid fortification
Elena Záppoli	LATIN AMERICA	Chair of Latin American network RELABEH, Former President Asociación para Espina Bifida e Hidrocefalia (APEBH)

Friday July 15th 2022
3 PM Brussels Time
9 AM Eastern Time
6.30 PM India Time
Online Zoom Webinar

More information: www.ifglobal.org | Registration: <https://bit.ly/PoAdv2>

SPECIAL FOCUS DURING THE 29th INTERNATIONAL CONFERENCE ON SPINA BIFIDA AND HYDROCEPHALUS

The 29th International Conference on Spina Bifida and Hydrocephalus with the theme Diverse Needs, Same Rights took place from September 6 to 9. On September 7 a special conference day was organised with a focus on prevention. The session on this day was moderated by Dr Sylvia Roozen from IF and Dr Luz DeRegil from the WHO.

Keynote speaker Dr Johnson, an international professional with over 48 years of New Product Development, Quality Assurance, Food Safety and Regulatory Affairs experience in the milling and baking sectors of the food industry from Canada, presented on Food Fortification: Scalable Approaches to Reduce Risks of Neural Tube Defects. In his keynote lecture, he provided examples on his contribution to prevention in supporting partnerships of millers, governments, vitamin and mineral suppliers, international organisations, and academic institutions to implement fortification efforts at local, regional and global levels.

The second keynote lecture was presented by Prof Dr Wertelecki, director OMNI-NET Ukraine, and Diana Akhmedzhanova, head of information and analytics department, project and data manager for OMNI-NET as part of the EUROLINKCAT collaboration. In this keynote lecture, activities were shared from the collaboration OMNI-NET has with a consortium of over 20 children hospitals in Ukraine, but also with administrations and medical facilities, medical universities and public organisations to improve awareness, birth defects monitoring, research, improve diagnosis and prevention, and develop strategies of early intervention and medical care in Ukraine. This second keynote lecture shed a light on reality in science and practice in times of war in Ukraine. This was in particular of interest to the countries in Europe to learn from support systems in times of war.

The third keynote speaker was Diana Akhmedzhanova, the Legal Entity Appointed Representative (LEAR) from OMNI-Net Ukraine in EUROLINKCAT - the European Union's Horizon 2020 Project and the data manager in Ukrainian part of collaboration study of OMNI-Net Ukraine and International consortium on Fetal Alcohol Spectrum Disorders. Diana Akhmedzhanova presented on the population-based surveillance of Neural Tube Defects in two regions in Ukraine.

KEYNOTE SPEAKERS

Dr Quentin Johnson

Dr. Quentin William Johnson is a professional with 48 years of New Product Development, Quality Assurance, Food Safety and Regulatory Affairs experience in the milling and baking sectors of the food industry.

For the past 26 years, he has provided technical assistance in 97 countries worldwide in the design, development and implementation of staple food fortification programmes with particular reference to wheat flour and maize meal fortification with Folic Acid, B group vitamins, iron and Zinc.

In 2011, Dr Quentin Johnson received an Honorary Degree of Doctor of Laws, honoris causa by the University of Guelph, Canada for his contribution to the advancement of staple food fortification around the world.



KEYNOTE SPEAKERS

Prof dr Wladimir Wertelecki



Wladimir Wertelecki is a Ukrainian-American physician and Emeritus Professor and Chairman from the University of South Alabama where in 1974, he established one of the first free-standing Department of Medical Genetics. Among his goals was the successful creation of a regional network of clinics across southern Alabama and West Florida.

Following an initial sponsorship by USAID, he established OMNI-Net programs in Ukraine, a not-for-profit network to provide training and to engage Ukrainian professionals to conduct monitoring of the frequency of birth defects.

KEYNOTE SPEAKERS

Diana Akhmedzhanova



Diana Akhmedzhanova is the head of Information and Analytics Department, Khmelnytskyi City Childrens Hospital (Khmelnytskyi, Ukraine).

Diana is the Legal Entity Appointed Representative (LEAR) from OMNI-Net Ukraine in EUROLINKCAT - the European Union's Horizon 2020 Project and the data manager in Ukrainian part of collaboration study of OMNI-Net Ukraine and International consortium on Fetal Alcohol Spectrum Disorders funded by U.S. National Institutes of Health - National Institute of Alcohol Abuse and Alcoholism - a cohort study of alcohol consumption and nutrient status of pregnant women and their pregnancy outcomes.


Following the keynote speakers, the sessions on prevention included other speakers from IF and IF partners such as WHO, Micronutrient Forum, and Food Fortification Initiative.

Decisions about prioritising effective prevention approaches to pursue in the near future are important. For individuals with Spina Bifida and Hydrocephalus and their families, multidisciplinary care calls for an improved approach, recognizing the reality of the complexity between science, practice, and policy.

DAY 2	
SEPTEMBER · 7 · 2022	HOURS IN PM (CEST)
WORD OF WELCOME	2.00 - 2.10
<i>Dr Sylvia Roozen & Dr Luz DeRegil (WHO)</i>	
KEYNOTE 1: Quentin Johnson - Food Fortification: Scalable Approaches to Reduce Risks of Neural Tube Defects	2.10 - 2.30
SESSION III PREVENTION	2.30 - 3.30
<i>Moderator: Prof dr Jacques Scheres</i>	
<i>15-min-Regular-Oral Presentations</i>	
TALK 19: Ayoub Al-Jawaldeh - The WHO Eastern Mediterranean Journey on Fortification and Prevention	
TALK 20: Maria Nieves Garcia Casal - Development of WHO guidelines on staple foods fortification from the interim consensus statement in 2009 to the current guidelines	
TALK 21: Saskia Osendarp - Effective Interventions for Micronutrient Deficiencies	
TALK 22: Hildur Önnudóttir - From Local to Global - How to Influence International Actions through National Advocacy	
BREAK	3.30 - 3.45



	HOURS IN PM (CEST)
SESSION IV PREVENTION	3.45 - 4.45
<i>Moderator: Prof dr Jacques Scheres</i>	
<i>Give-me-5-min Presentations</i>	
TALK 23: Vijaya Kancharla - A 2020 Global Update on Folic Acid-preventable Spina Bifida and Anencephaly through Mandatory Fortification of Cereal Grains	
TALK 24: Camilla Aukrust - Comprehensive Policy Recommendations for the Management of Spina Bifida and Hydrocephalus in Low Resource Contexts	
TALK 25: Boris Groisman - Prevention of Neural Tube Defects in Argentina	
<i>15-min-Regular-Oral Presentations</i>	
TALK 26: Helena Pachón - Folic Acid Fortification: The Safe and Effective Action towards Spina Bifida Prevention	
TALK 27: Scott Montgomery - Smarter Futures: A Public-private-civic Partnership	
Q&A	
CLOSING	4.45 - 5.00



IF STATEMENT

In September, IF published the statement: A call for a global action to reduce the prevalence of Neural Tube Defects worldwide. This statement outlines (1) what NTDs are, (2) how NTDs are affected by the social determinants of health, (3) what food fortification is and how it reduces the prevalence of NTDs, (4) the economic benefits of food fortification, (5) the stakeholders that need to be involved to make mandatory fortification of staple foods with folic acid a global reality, (6) the primary prevention of NTDs in the context of disability rights, (7) the need for an effective rights-based approach for the primary prevention of Spina Bifida and other NTDs, (8) IF's recommendations on achieving a global reduction in the prevalence of NTDs through food fortification.

COMMUNITY BUILDING AND TWINNING

IF ACTIVITIES WITH MEMBERS

MEMBERS MEETINGS

On a global scale, IF held regular members meetings with presidents of IF member associations. These member meetings allowed for a reflection on the highlights of previous year activities, defining specific needs, and setting priorities of IF members. IF also facilitated meetings per region. For instance, IF has held member meetings with the Asia-Pacific Network SBH and the IF-RELAEBHI (Spanish-speaking countries). Furthermore, meetings were exclusively held for communications coordinators of member associations to express their needs, discuss challenges they encounter and how support can be provided both by IF and IF members.



WEBINARS

To increase the capacity of EU member associations of IF and reinforce cooperation, several webinars were designed in the spring and autumn focused on the topics relevant for the Spina Bifida and Hydrocephalus community, including ageing with SBH, youth with SBH, and women with SBH. The spring and autumn webinars were focused on enhancing knowledge and sharing best practices among countries. The spring webinar was held on July 15, 2022, which was an experience exchange webinar named IF webinar 'Learning from Experience: Strategic Advocacy for Primary Prevention'. This webinar was an experience exchange and twinning opportunity for all IF members, in which representatives from Africa, Asia-Pacific, Latin-America and Europe who have advanced their national advocacy for primary prevention shared their key element of success, the process, lessons learned and advice for all participants. The webinar was a great opportunity for all IF members to learn from each other and enhance their capacity regarding advocacy and policy.



The autumn webinar was strategically organised in the awareness month of October as part of the World Spina Bifida and Hydrocephalus Day 2022. The webinar served as the best month as it kept the momentum going along the awareness campaigns and had the involvement of different stakeholders celebrating in this month. The webinar consisted of four regional meetings organised by IF in collaboration with member association ASBI Italy. The meetings covered four themes: Transitional care, Spina Bifida registry, the path towards independence, and disability and sport.



TRAININGS

The annual thematic training for IF members was titled 'From local to global: How to influence international actions through national advocacy' and divided into two training parts.

Training part 1 was held online between 2nd of March and 27th of April. These were one-on-one sessions carried out between the IF Policy Officer and individual IF members. The primary objective of the training part 1 was to support and empower IF members to commence advocacy activities for a global awareness and policy change for the primary prevention of spina bifida through food fortification. Alongside, IF members received training packages with all necessary materials. As IF members were based around the world with different needs and capacity levels, training part 1 aimed to better provide relevant knowledge and skills considering IF's diverse membership.

Training part 2 was held online on 6th of May. This was a group training open to all IF members. This training focused on sharing and knowledge exchange, along with discussing questions and concerns from IF members. The objectives of the group training was to provide an open space for questions and answers from IF members, and provide IF members with concrete tools to join the advocacy towards international organisations from the national level by clearly understanding:

- What international organisations are and how they work;
- Why international organisations play an important role for the advancement of the rights and needs of the SBH community;
- How international actions have an impact on the national and local level;
- How national level advocacy impacts actions on the international level.

The IF members training materials, included: Information package on global prevention through food fortification; An infographic that can be used when contacting policy makers; A draft letter on advocacy towards the WHO for food fortification that can be sent by SBH associations to policy makers (with instructions).

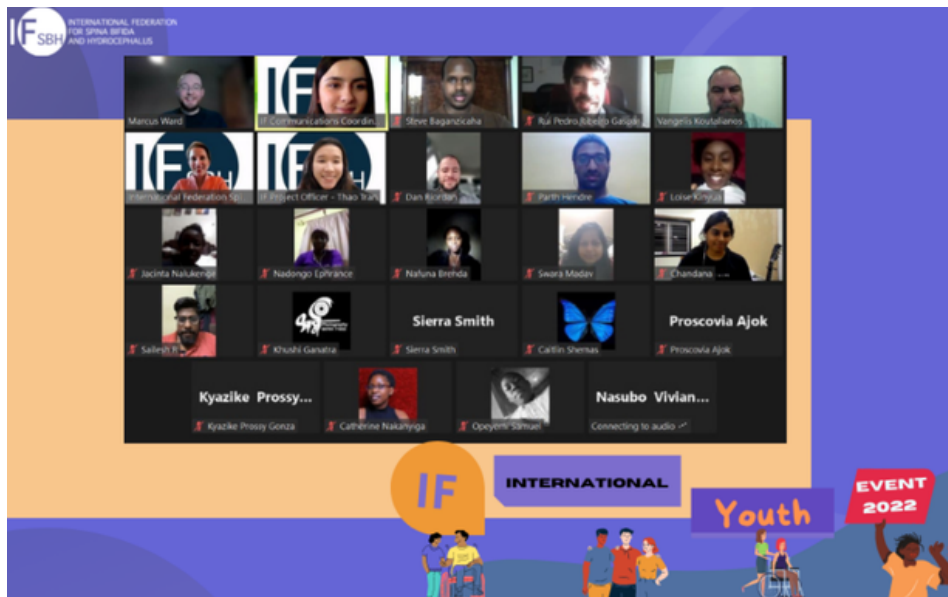


ACTIVITIES IF ADVISORY GROUPS

IF INTERNATIONAL YOUTH GROUP SBH

MEETINGS

The youth group SBH represented a total of 10 young persons with SBH, four males and six females aged 18 to 30 years from different countries around the world. During online meetings they discussed ways to address important issues relevant for them. The youth focused on their key topic of the year during these meetings, independent living.



TRAININGS

On the occasion of the 29th International Conference for Spina Bifida and Hydrocephalus – Diverse Needs, Same Rights, IF in collaboration with the European Network on Independent Living (ENIL), organised a pre-conference workshop on Independent Living taking place on September 5 2022. During this workshop the youth were empowered to advocate for their rights to live independently.

PUBLICATIONS

The activities of the pre-conference workshop was documented in the 29th International Conference on Spina Bifida and Hydrocephalus - Diverse Needs, Same Rights Programme Book. In addition, the published IF Statement on independent living gained the contribution of the IF youth group, to ensure that the experiences of the young people are reflected.

Independent Living for Youth with Spina Bifida and/or Hydrocephalus

Register now and meet Kamil Goungor at the pre-conference workshop during the 29th International Conference on Spina Bifida and Hydrocephalus - Diverse Needs, Same Rights!

Who is Kamil Goungor?

- Co-founder and chair of living the first and only Independent Living organisation in Greece
- Policy and Movement Support Officer at the European Network on Independent Living
- Represents the ENIL Youth Network at the Youth Committee of the European Disability Forum
- Member of the Youth Committee of the International Disability Alliance
- Travel blogger in Greece (Bihetrotseer)

KAMIL GOUNGOR

"Independent Living means to have choice and control over your life, like non-disabled people have and take for granted. Even the right of doing mistakes or taking wrong decisions is part of it!"

"All policies, on all levels, should be fully in line with the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), which addresses Independent Living in the article 19, as well in the General Comment no 1"

WORKSHOP DETAILS

- Monday 5th of September 2022
- 2 PM - 4 PM CEST
- 4 AM - 10 PM EST
- 5:30 PM - 7:30 PM IST
- Youth with disabilities between 18 - 35 years old
- Online, Zoom

Agenda & Registration → <https://bit.ly/C25BH29>

VISIBILITY

On the occasion of the 29th International Conference on Spina Bifida and Hydrocephalus – Diverse Needs, Same Rights, Rebecca Austin from the IF youth group presented the work with the community.

On the occasion of the Global Disability Summit, IF member Anđela Radovanović, programme manager at the Association of Youth with Disabilities of Montenegro, shared insights into an inclusive policy model of health. She strongly recommended youth to become actively involved with their national associations to advocate for a more inclusive policy model of health.



The IF youth group also raised awareness during the International Youth Day and created a toolkit to celebrate the young people with SBH around the world.

Additionally, IF and IF Youth Group joined the Freedom Drive organised by the European Network on Independent Living – ENIL where over 200 disability activists march between Cinquantenaire and the European Parliament to demand an end to institutionalisation and the right to independent living.



IF WORKING GROUP ON AGEING WITH SBH

MEETINGS

In 2022, the working group on ageing consisted of eight IF member representatives, including Kevin O'Donnell, Chair of the Working Group on Ageing with SBH (Scotland), Hazel McGeough (Ireland), Mario Sel (Belgium), Teije Dijk (the Netherlands), Filipe Pereira (Portugal), Eva Toft (Sweden), Judy Thibadeau (USA), and Martin Duff (Australia). The group continued their meetings to discuss ways to improve our understanding of the lived experiences of older persons with SBH. Meetings were focused on discussing surveys and conducting interviews for the report published later in the year.



IF Working Group on Ageing



KNOWLEDGE GATHERING

The working group developed a survey to gather several best practices of SBH associations targeted to the ageing SBH community. The surveys were followed up with in-depth interviews. These actions were essential in forming the best practices report later in the year.

VISIBILITY

On the occasion of the 29th International Conference on Spina Bifida and Hydrocephalus – Diverse Needs, Same Rights IF Working Group on Ageing's Chairman, Kevin O'Donnell, highlighted the latest activity of the group. In particular, Kevin shared some of the results of a survey developed by the group, which were followed up with a number of interviews with various SBH associations on the best practices around the world to address challenges faced by the ageing SBH community. Several recommendations were also provided.

Furthermore, during the Global Disability Summit side event the chair of the working group, Dr Kevin O'Donnell, provided perspectives on what person-centred care means for a person with Spina Bifida. Moreover, the recent work by the ageing working group was used as an example.

The International Federation for Spina Bifida and Hydrocephalus invites YOU to the 29th Conference on Spina Bifida and Hydrocephalus **Diverse Needs, Same Rights**

From September 6th - 9th
2pm - 5pm (CEST)

Mario Sel

"I made a wheelchair trip of 300 km within 10 days. It went beyond my expectation and has changed my life. I have made many new friends, connected and empowered other people, increased awareness about SBH and raised a total of 26.000 euros."

Day 2 • September 7, 2022
"Side to Side, a Wheelchair Trip in 10 days from the East to the West of Flanders, Belgium"

PUBLICATIONS

Following several knowledge gathering activities, the IF Working Group on Ageing published its report 'Ageing With Spina Bifida and Hydrocephalus: An Overview of Best Practices Around the World'. Having described the problems associated with ageing with SBH in previous reports, the IF Working Group on Ageing turned its attention to solutions. Interviews with IF member associations were held to identify best practices with respect to the needs and support for ageing with SBH from IF member associations, so that these could be explored and shared. Therefore, the study within the report aimed to gain deeper insights into what is happening on a country level, what are needs from older individuals with SBH and identify best practices by IF member associations around the world to support their ageing SBH community.

Table 1. An overview of best practices

Countries	Challenges experienced by ageing SBH community	Best practices	Objectives
Uganda	<ul style="list-style-type: none"> Absence of job training and job opportunities for adults with SBH 	Rehabilitation Centre	<ul style="list-style-type: none"> Offer training and employment assistance to people with SBH Create jobs for people ageing with SBH Empower adults with SBH to become self-reliant and self-worth in the society
The USA	<ul style="list-style-type: none"> Lack of platform for sharing and discussion Feelings of loneliness and social isolation 	Virtual gathering	<ul style="list-style-type: none"> Create a positive, safe and educational space for sharing and discussion Strengthen the relationship within ageing SB community
South Africa	<ul style="list-style-type: none"> Absence of medical history of adults with SBH Insufficient knowledge and understanding of novice medical staff about SBH and ageing with SBH 	Record card	<ul style="list-style-type: none"> Record the medical history of the persons ageing with SBH Ensure that potentially serious complications are evaluated by medical staff appropriately with undue delays in treatment Educate novice medical staff who may be unfamiliar with SBH

Table 1. An overview of best practices

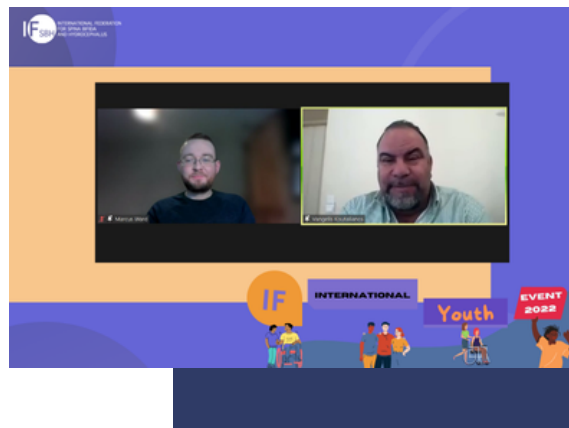
Countries	Challenges experienced by ageing SBH community	Best practices	Objectives
Belgium	<ul style="list-style-type: none"> Lack of opportunities for social interaction Feelings of loneliness and social isolation 	Road trip	<ul style="list-style-type: none"> Bring people ageing with SBH together Provide an enjoyable reasonable-priced road trip Educate older people with SBH about different aspects of ageing with SBH
Malaysia	<ul style="list-style-type: none"> Insufficiency of knowledge related to living with SBH at older ages Lack of connection with other persons ageing with SBH and specialists 	Regional Workshop	<ul style="list-style-type: none"> Raise awareness of persons with SB about their ageing issues in different areas Strengthen the relationship within the SB community Connect SB ageing community with their
Scotland	Resources and information related to ageing with SBH are not accessible	Online Ageing Hub	
The Netherlands	<ul style="list-style-type: none"> Lack of platform for sharing and discussion Feelings of loneliness and social isolation 	Online Workshop	



TWINNING

IF INTERNATIONAL YOUTH GROUP MEET & GREET WITH VANGELIS KOUTALIANOS

On February 25 2022, the IF International Youth Group SBH held a Meet & Greet with Vangelis Koutalianos, a motivational speaker born with Spina Bifida from Greece. During this event, young participants between the ages of 18 to 35 had a chance to listen and chat with a motivational speaker from Greece with Spina Bifida, Vangelis Koutalianos. He shared with all the participants lots of interesting and inspiring life stories. Despite having lost his ability to walk at the age of 35, Vangelis – a strong, positive and independent man – has found his strength to happily confront this obstacle. Vangelis is also a real adventurer with his travelling experiences such as going on a boat to discover an island, riding a camel in Dubai and riding an elephant in Thailand. Besides, Vangelis shared valuable tips for young participants regarding relationship, safe travelling, working and daily life situations.



IF GRAND ROUNDS

IF continued to facilitate meaningful discussions and opportunities for medical education among healthcare professionals working with individuals with Spina Bifida and or Hydrocephalus. The so-called Grand Rounds provided a forum to share clinical expertise and best practices among physicians. The first Grand Round session on Incontinence Management with Dr Santosh Karmarkar was held on February 11 2022. The second Grand Round session on Hydrocephalus with Dr Benjamin Warf was held on April 8 2022. The third Grand Round session was held on Fetal Surgery with Dr Agnieszka Pastuszka on August 12 2022.

GRAND ROUNDS FOR CLINICIANS
11 FEBRUARY 2022 | 9 AM EST | 3 PM CET | 7.30 PM IST

Dr Santosh Karmarkar
Founder Trustee
Spina Bifida Foundation, India,
Pediatric Surgeon & Urologist, Mumbai

TOPIC
INCONTINENCE MANAGEMENT FOR SPINA BIFIDA

REGISTRATION:
[HTTPS://BIT.LY/IFGRD1](https://bit.ly/IFGRD1)

IF SBH INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

GRAND ROUNDS FOR CLINICIANS
8 APRIL 2022 | 9 AM EST | 3 PM CEST | 6.30 PM IST

Benjamin C. Warf MD
Professor of Neurosurgery
Harvard Medical School,
Hydrocephalus and Spina Bifida Chair
Director of Neonatal and Congenital
Anomaly Neurosurgery
Boston Children's Hospital;
Chairman
Neuro Kids (www.neurokids.us)

TOPIC
HYDROCEPHALUS

REGISTRATION:
[HTTPS://BIT.LY/IFGRD2](https://bit.ly/IFGRD2)

IF SBH INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

GRAND ROUNDS FOR CLINICIANS
12 AUGUST 2022 | 9 AM EST | 3 PM CEST | 6.30 PM IST

Dr Agnieszka Pastuszka
Pediatric Surgeon, Urologist and Fetal Surgeon
Member of the European Club for Fetal Surgery (EFCS)
International Continence Society (ICS) assistant at the
Clinic of Children's Surgery and Urologist, Medical
University of Silesia in Katowice, Poland

TOPIC
FETAL SURGERY

REGISTRATION:
[HTTPS://BIT.LY/IFGRD3](https://bit.ly/IFGRD3)

IF SBH INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

The 29th INTERNATIONAL CONFERENCE ON SPINA BIFIDA AND HYDROCEPHALUS DIVERSE NEEDS, SAME RIGHTS

One of the highlights in the year 2022 was that our federation organised the 29th International Conference on Spina Bifida and Hydrocephalus Diverse Needs, Same Rights (taking place from September 6 to 9 with a pre-conference workshop on September 5). Together with the conference scientific committee an ambitious programme for this conference has been conceived and designed with speakers from all around the world. This four-day conference with three keynote lectures, 43 talks, and 10 sessions was a great success. The theme of the 29th international conference was voted for by IF members. The conference programme with its international speakers reflects key topics relevant to the SBH community including education, employment, skills training, healthcare and other public services, and a full participation in society which includes being a stakeholder in policy and decision-making. This contributes to an inclusive society, where people with SBH and their families can enjoy all rights on an equal basis and access to all opportunities including.

IF SBH INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

MEYER *RespiCare* Spine

INTERNATIONAL CONFERENCE ON SPINA BIFIDA AND HYDROCEPHALUS
10th - 12th Aug, 2018 | Venue : Le Meridien, New Delhi, India

International 10th - 12th August 2018

International 10th - 12th August 2018

The 29th International Conference on Spina Bifida and Hydrocephalus
Diverse Needs, Same Rights

Programme Book
5th - 9th September 2022

4 day conference

10 sessions

3 keynote & 43 speakers

900 participants
44K audience reached

Drawing picture: Winner of the IF WSBD21 drawing contest Francisca Rojo Cano (24) from Chile

The first keynote speaker was Dr Johnson, an international professional with over 48 years of New Product Development, Quality Assurance, Food Safety and Regulatory Affairs experience in the milling and baking sectors of the food industry from Canada. In his keynote lecture, examples were shared on his contribution to prevention in supporting partnerships of millers, governments, vitamin and mineral suppliers, international organisations, and academic institutions to implement fortification efforts at local, regional and global levels.

The second keynote lecture was presented by Prof Dr Wertelecki, director OMNI-NET Ukraine, and Diana Akhmedzhanova, head of information and analytics department, project and data manager for OMNI-NET as part of the EUROLINKCAT collaboration. In this keynote lecture, activities were shared from the collaboration OMNI-NET has with a consortium of over 20 children hospitals in Ukraine, but also with administrations and medical facilities, medical universities and public organisations to improve awareness, birth defects monitoring, research, improve diagnosis and prevention, and develop strategies of early intervention and medical care in Ukraine.

This second keynote lecture shed a light on reality in science and practice in times of war in Ukraine. This was in particular of interest to the countries in Europe to learn from support systems in times of war. The conference programme reflects key topics relevant to the Spina Bifida and Hydrocephalus community. On the first day of the conference, the conference workshop was focussed on independent living for youth with Spina Bifida and or Hydrocephalus.



The conference workshop 'Independent living for youth with Spina Bifida and/or Hydrocephalus' was co-moderated by Kamil Coughor, an experienced professional advocate for independent living and included a guest speaker from the IF International Youth Group SBH. The session was exclusively for youth with disabilities. During the session the participants learned about the history of the independent living movement. The UN Convention on the Rights of Persons with Disabilities and current debates within the field, such as whether family members can be considered to be personal assistants. Through the use of a survey and an interactive session. A role playing game, participants were encouraged to think about and share what the right to independent living means to them, and what it means in the context of their community.



The country updates are an important part of twinning, because one shares and exchanges the IF relevant activities in countries. On the second day of the conference, IF members shared their country updates in 5-min presentations. The third day was a highlight of the conference where international speakers focussed on effective strategies on prevention as well as a human right approach towards prevention. The fourth day focused on perspectives from individuals with SBH, parents, and healthcare professionals. Last but not least, on the fifth day reflections were shared on surgical care in the Global South as well as surgical management from other countries' perspectives.



During this conference IF facilitated further discussion regarding challenges such as prevention and integrated care that now address the Spina Bifida and Hydrocephalus community. This conference covered a variety of aspects of care for individuals with Spina Bifida and or Hydrocephalus, from very fundamental issues to practical applications. It was designed to be interesting for everyone improving prevention, care and management.

EUROPEAN REFERENCE NETWORKS

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

During 2022, IF continued to be an active member of ERN-ITHACA as the patient representative organisation for Spina Bifida and other dysraphisms. Together with the chairs of the ERN-ITHACA Working Group Spina Bifida, IF identified opportunities for knowledge gathering activities, sharing best practices during IF Grand Rounds, the 29th International Conference on Spina Bifida and Hydrocephalus - Diverse Needs, Same Rights as well as exploring routes for twinning opportunities. Moreover, IF was an invited keynote speaker during the European conference organised by EUROLINKCAT on health and education outcomes of children across Europe with congenital anomalies. IF presented on a multi-stakeholder engagement to support person-centred health outcomes.



Trans-ERN Working Group for Spina Bifida (Spinal Dysraphism) Workshop for Future Research



WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY

Established and designated by the General Assembly in Guatemala 2011 of IF, the international conference on World Spina Bifida and Hydrocephalus Day 2022 (WSBHD22) is a yearly event that serves to raise awareness of the rights and needs of the SBH community as well as the UNCRPD.

This year, the World Spina Bifida and Hydrocephalus Day 2022 was a special highlight as it marked the 10th edition to raise global awareness. On this day, IF together with her worldwide members organised a conference and several side events, launched a talent show, and led an impactful awareness raising campaign on social media. In addition, IF members organised specific activities such as other campaigns on social media, conferences, and outdoor activities.

WSBHD22 'Elevate Your VOICE'

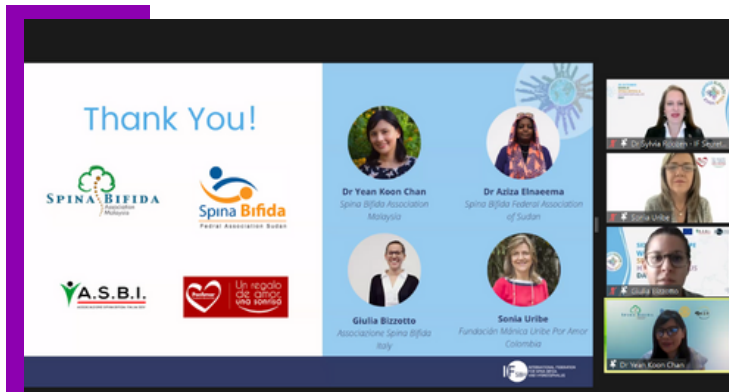
WSBHD22 with the theme 'Elevate Your Voice' was held on Tuesday, October 25th 2022 on the Zoom platform and was live streamed via YouTube. The conference consisted of an international audience and presentations from IF members as speakers all around the world who shared their regional focus on this year's theme Elevate your Voice.

The first speaker, Dr Yean Koon Chan from IF member association SIBIAM in Malaysia covered the theme 'Elevate Your Voice - My Voice Matters'. Based on this theme, SIBIAM organised a colouring contest for children of different age groups as many children were not able to express themselves verbally. Dr Chan acknowledged all of the contributions of persons with SBH.

Inclusion is defined as "the action or state of including or of being included within a group or structure". Another definition for inclusion is "the practice or policy of providing equal access to opportunities and resources for people who might otherwise be excluded or marginalised, such as those who have physical disabilities". To me, inclusion means being included or being a part of something

- Narresh, person with Spina Bifida from IF member association SIBIAM, Malaysia

Dr Aziza Elnaema, from IF member association Spina Bifida Federal Association, Sudan organised a regional meeting focusing on the theme 'Elevate your Voice to Rehabilitation for a Creative Life'.





Giulia Bizzotto from IF member association ASBI Italy, the third speaker, shared how ASBI has decided to focus on the theme 'Elevate Your Voice to the Path Towards Independent Living', focusing on autonomy and independent living. Giulia mentioned the four side events that were organised by ASBI and shared some aspects during these events. Giulia highlighted how during these events the discussion was focused on the need for transitional care and multidisciplinary teams to treat persons with SBH as a whole, the need for a Spina Bifida registry as a best practice, the importance of autonomy of persons with SBH, and the last and upcoming side event on disability and sports.

The fourth and last speaker, Sonia Uribe took the virtual stage and talked on the theme of Fundación Mónica Uribe Por Amor Colombia 'Elevate Your Voice to Independent Living and Autonomy.' She highlighted the importance of empowering persons with SBH as well as their families, using sports as a tool for improving lives of the children, the impact of the elderly community on the lives of young children, and for persons with SBH to have the possibility to share feelings. Sonia also emphasised how every individual have to know themselves and work towards being owners of their condition:

Sonia then gave the floor to Maria to share her testimony as a person with SBH. Maria has a PhD in Molecular Biology and shared how the Fundación Mónica Uribe Por Amor Colombia formed an essential part of her life and supported her and her mother in better understanding her condition.

"There are no barriers or limits to a great discipline and willingness"

- Maria, person with Spina Bifida and Hydrocephalus from IF member association Fundación Mónica Uribe Por Amor Colombia

**25 OCTOBER
WORLD
SPINA BIFIDA &
HYDROCEPHALUS
DAY**

**WSBHD22 ELEVATE
YOUR VOICE
IF SBH**

ELEVATE YOUR VOICE

Why "Elevate Your Voice"?

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

The UNCRPD represents a major milestone in the continued advancement of the rights of persons with disabilities. The convention outlines the human rights and fundamental freedoms of persons with disabilities and the obligations of States Parties to the UNCRPD to advance and protect those rights.

Accessibility and inclusion are challenges frequently encountered by persons with SBH. With stigma, discrimination and lack of awareness creating further barriers to the full enjoyment of life. Therefore, IF shares with you the theme for the World Spina Bifida and Hydrocephalus Day 2022: "Elevate Your Voice".

Join IF in elevating your voice!

#ElevateYourVoice

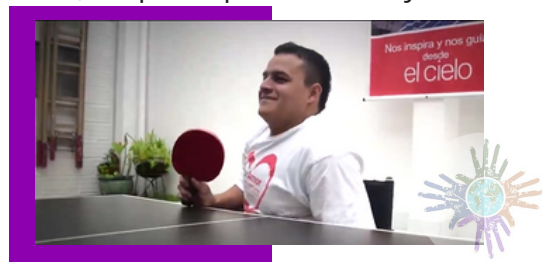
WSBHD22 TALENT SHOW

The IF WSBHD22 Talent Show was launched on October 25 2022 where the community with Spina Bifida and Hydrocephalus from around the world joined and shared their talents. The types of contributions ranged from persons with SBH who were active in sports, music, dancing, singing, or were engaged in storytelling.

The talent show was an integral part in supporting members' advocacy and increasing visibility of the SBH communities. Prior to the conference, all persons with SBH were welcomed to share their talents with the world by sending an MP4 recording of maximum 10 minutes to be broadcasted on IF's YouTube channel on the occasion of the World Spina Bifida and Hydrocephalus Day 2022. IF received 16 contributions in total for the talent show contest.

The types of contributions ranged from persons with SBH who were active in sports, music, dancing, singing, or were engaged in storytelling. During the conference, the talent show results with the top three winners were announced showing the many talents of persons with SBH all around the world. The process of choosing a winner consisted of the SBH community entering their votes through a form on the WSBHD website. The winners were:

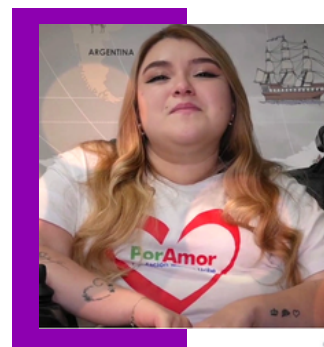
- **1st place: Juan** - Sports. Juan is a 33-year-old young man with Spina Bifida and is a true sports passionate. From swimming to table tennis, he participates in many tournaments in Colombia;



- **2nd place: Jesús** - Violin. Jesús is a 22-year-old young man who was born with myelomeningocele in Paraguay and is a talented musician who plays violin;



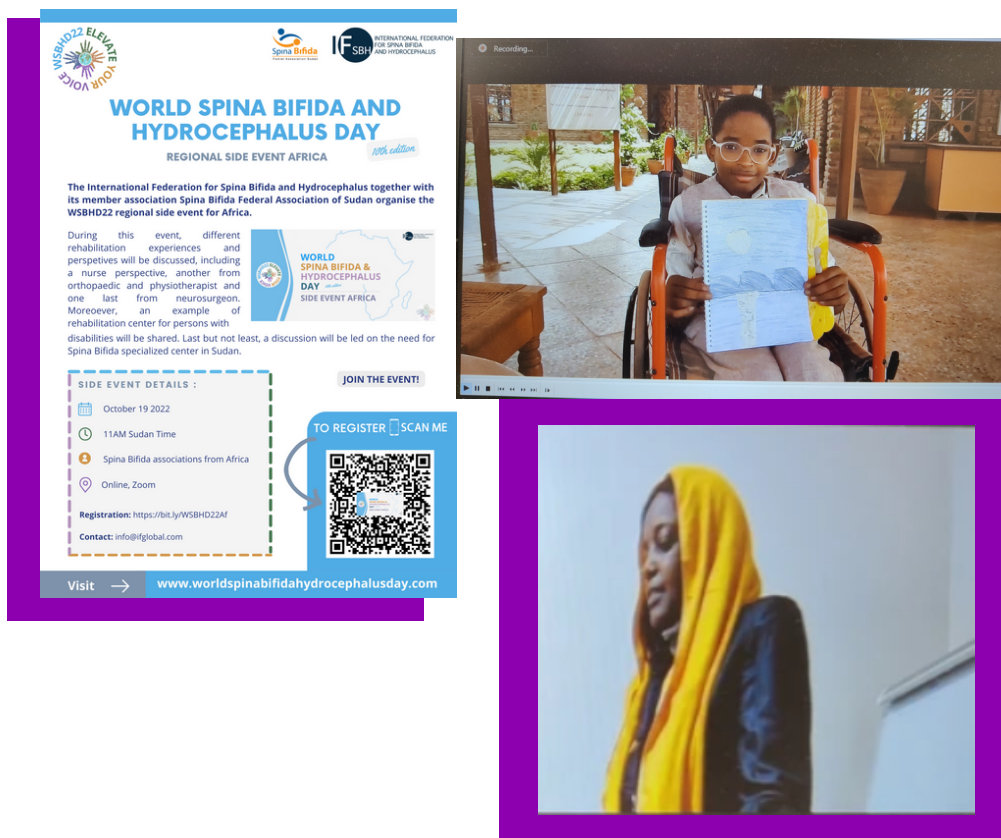
- **3rd place: Kelly** - Singer. Kelly Vanessa is a young woman with Spina Bifida from Colombia who has an incredible voice and loves to sing.



SIDE EVENT AFRICA

IF member association, Spina Bifida Federal Association of Sudan, together with IF held a regional side event on the occasion of the WSBHD22 on the theme of 'Rehabilitation for a Creative Life'. During this event, different rehabilitation experiences and perspectives were discussed, including a nurse, neurosurgeon, orthopaedic and physiotherapist perspective. Moreover, an example of a rehabilitation centre for persons with disabilities was shared. Lastly, a discussion was led on the need for Spina Bifida specialised centre in Sudan.

Speakers involved in these side events were Dr Muhab Elmahdi, Neurosurgery Specialist SUH & Assistant Professor Department of Surgery UofK, who gave the perspective on the role of neurosurgeons in Spina Bifida management and rehabilitation. Dr Nagla Mohammad, Assistant Professor School of Nursing UofK gave a nurse perspective on incontinence beyond infancy. Speaker Tariq Abdalla, Senior Lecturer Physiotherapy Department of Ahfad university for Women, provided a speech on physiotherapy in Sudan. Dr Hassan Alnour, PhD Physiotherapy, gave a talk on Spina Bifida and physiotherapy rehabilitation. Professor of Orthopaedic SUH UofK Samir Shaheen, gave a speech on orthopaedic management and the challenges of Spina Bifida patients in Sudan. Dr Aziza Elnaema, consultant paediatric surgeon/paediatric urologist SUH, Ahfad University for Women, gave a talk on the Spina Bifida Center in Sudan. Lastly, professor of surgery UofK P. Ahmed Hassan gave a creative example of a rehabilitation centre in Sudan.



SIDE EVENT AMERICAS

IF member association, Fundación Mónica Uribe Por Amor (Colombia) organised together with IF, a regional side event to the WSBHD22 on the theme of 'Independent Living and Autonomy' where several testimonials from self-employed persons with SBH and professionals were shared. Speakers included Berny Bluman, consultant and business speaker on issues related to inclusion, accessibility and management of transformation and crisis. Testimonials were given by Juan Felipe González and María Cecilia Agudelo. More than 110 families attended this side event.





INTERNATIONAL FEDERATION
FOR SPINA BIFIDA
AND HYDROCEPHALUS

Organiza





Conferencista
Berny Bluman



Testimonio
Juan Felipe González



Testimonio
María Cecilia Agudelo

Autonomía y vida independiente

25 de Octubre 2022

Encuentro Latinoamericano de Espina Bífida

The International Federation for Spina Bifida and Hydrocephalus together with Fundación Mónica Uribe Por Amor organises a regional side event for Latin American Spina Bifida and Hydrocephalus associations. This session will be on the topic of: **Independent Living and Autonomy**.

During this event, you will listen to four testimonials of self-employed persons with SBH. Moreover, there will also be experts with very active spinal cord injuries.

JOIN US!

SIDE EVENT DETAILS :

-  October 25 2022
-  2PM Colombia Time
-  Spina Bifida associations from Latin America
-  Online, Zoom

Agenda & Registration
Visit: <https://fundacionporamor.org/>
Contact: coordinacion@fundacionporamor.org



Visit → www.worldspinabifidahydrocephalusday.com

SIDE EVENT EUROPE

IF member association, ASBI Italy, together with IF organised the WSBHD22 regional side event for Europe. This side event was held through four sessions and covered four themes: Transitional care, Spina Bifida Registry, The path towards independence and Disability and sport.

The session of transitional care was held On 5 October 2022 moderated by Dr Giovanni Mosiello, head of Continence Surgery and Neuro-urology at the Bambin Gesù paediatric hospital in Rome. The program included sessions both by clinician - in particular among the speakers were Dr Cretì Giuseppe, Director of Pediatric Urology at the Casa Sollievo della Sofferenza hospital Puglia, Dr Claudia Rendeli, Director of Spina Bifida and Congenital Uropathies at the Gemelli Polyclinic in Rome, Dr Paolo Gelli clinical psychologist and psychotherapist and Dr Adriano Ferrari surgeon specialising in neurology and physical medicine and rehabilitation at the University of Modena and Reggio Emilia - and from the point of view of persons living with Spina Bifida and/or Hydrocephalus. Ilaria Guidotti and Luigi Russo, members of the ASBI Italy Youth Group, brought their testimonies which then opened the discussion among the participants.



On October 14, the second meeting on Spina Bifida Registry was held on the occasion of the National Month of Spina Bifida and Hydrocephalus on the topic of the Spina Bifida Registry, moderated by Dr Domenica Taruscio, former director of the National Center for Rare Diseases of the Higher Health Institute. The program included sessions both by clinicians, in particular among the speakers there were Dr Paola Torreri, Dr Paolo Salerno of the National Center for Rare Diseases and Dr Tiziana Redaelli, director of the Niguarda Spinal Unit, as well as from the point of view of the representatives of the associations and persons with SBH. Benoit Fourcroy, representative in the working group for Spina Bifida within the ERNs and Mario Orgiana, vice president of ASBI Italy and President of ASBI Sardinia, brought their testimonies which then opened the discussion among the participants.



On October 18, the third meeting on the path towards independence was held, moderated by Dr Alessandra Leo, medical director at the Spinal Unit of the Niguarda in Milan. The program included sessions both by health professionals, in particular among the speakers there were Dr Alessandro Prisco occupational therapist and nurse Patrizia Ferroni, and from the point of view of the representatives of the Associations, young people and parents. Dr Giampiero Griffio co-director of the Center for the study of disabilities, Elide Bruna and Laura Rosillo Beneyto respectively members of ASBI and IF Youth Group, Alessia Varesi parent of a boy with Spina Bifida and Kevin O'Donnell, welfare counsellor at the Scottish Association and chair of the IF Working Group on Ageing with SBH, brought their testimony which then opened the discussion among the participants.

On October 26, the fourth meeting was on the topic of sport, moderated by Roberto Bof, who for 40 years has been a sport journalist of the Paralympic Games. The program included sessions both by health professionals, among the speakers there were Dr Maria Taverna, medical director at the Spina Bifida Center of the Meyer Hospital in Florence, and representatives of the Associations, young athletes with Spina Bifida and parents. The President of the Italian Paralympic Committee Luca Pancalli opened the meeting, then Federico Mancarella, bronze in KL2 200 at the last Paralympics in Tokyo, Sofia Brunati, rising star of Paralympic fencing and Cillian Dunne, Irish wheelchair racing athlete, intervened. Points of view were also shared by Nicola Busata ski instructor with specialisation in teaching to people with disabilities and technical director of Freerider Sport Events as well as from Emanuele Castorino and Roberto Gerevini parents of young people with Spina Bifida.



Elevate your voice to call society to ensure accessibility and inclusion to ALL and especially to persons with disabilities



We should continue joining forces to ensure that the rights of persons with Spina Bifida and Hydrocephalus are respected to fully enjoy their life, equal as anyone else!



WSBHD22 SIDE EVENTS

BY IF MEMBERS

The WSBHD was seen as an opportunity to raise awareness, advocate, and promote the rights of persons with Spina Bifida and Hydrocephalus, but also to show the strength of the SBH community through the activities of IF members. This was evident through the examples shown below.



IF member Association SHA-U, Uganda, together with the Ministry of Health organised the conference 'A call for National action to reduce the prevalence of birth defects through food fortification; folic acid supplementation and dietary diversity in the country'. The National Coordinator of Spina Bifida and Hydrocephalus Association of Uganda (SHAU) Ruth Nalugya asked women of child bearing age to watch what they feed eat and include vegetables, fruits and at least one tablet of Folic Acid to reduce the risk of giving birth to a child with such a defect. The Ministry of Health has revealed plans to deploy equipment and neurosurgeons to the different regional referral hospitals across the country in order to bring closer treatment and management of Spina Bifida and Hydrocephalus closer to the people.



IF members in Bangladesh celebrated through a joyful event at the Bangladesh Medical College on the World Spina Bifida and Hydrocephalus. Moreover, they were also covered in the local newspaper.



IF members Festus Fajemilo Foundation & Spina Bifida Hydrocephalus Association in Nigeria also organised activities for World Spina Bifida & Hydrocephalus Day 2022. Activities included media chats on Radio/T.V stations, a visit to Chief Medical Director - Lagos State University Teaching Hospital on advocacy to push for comprehensive continence management, a courtesy visit to the General Manager - Lagos State Office for Disability Affairs, and various social media campaigns.



IF member from Romania, Asociatia Romana de Spina Bifida si Hidrocefalie, celebrated the World Spina Bifida and Hydrocephalus Day 2022 by organising two important events, one in Bucharest and one in Sibiu. There were children, adults with Spina Bifida, parents, grandparents and neurosurgeons present. Furthermore, this was an excellent opportunity to exchange experience and to learn from each other.



IF members from Norway raised awareness of SBH on the World Spina Bifida and Hydrocephalus Day 2022. IF members **Ryggmargsbrokk- og hydrocefalusforeningen** opened a stand in Rikshospitalet in Oslo. They have also been out and delivered brochures to other hospitals and health centres around Norway to raise awareness of Spina Bifida and Hydrocephalus.

Finally, the NINS&H Bangladesh celebrated the World Spina Bifida and Hydrocephalus Day with a beautiful cake. The NINS&H Hospital in Bangladesh works with patients and families with Spina Bifida and Hydrocephalus with hope to achieve a quality life. On WSBHD22, a talk was held in the hospital together with the Hospital Director and joint director, including patients, guardians, hospital staff, nurses and doctors.



IF member Vlaamse Vereniging voor Spina Bifida en Hydrocephalus vzw (VSH) from Belgium, Flanders organised outdoor activities on WSBHD22. Three activities were planned with their members on Sunday October 23rd to celebrate the World Spina Bifida and Hydrocephalus Day 2022: they first held a presentation, then they went for a walk and finally they enjoyed a barbecue dinner altogether.

NETWORK DEVELOPMENT

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

IF has forged alliances with key partners in the disability and human rights sector including private and public initiatives by civil society and knowledge institutes. Throughout the year, IF provided its expertise in several meetings and events. Examples included an invited keynote lecture during the EuroLinkCat Conference 'Health and Education Outcomes of Children across Europe with Congenital Anomalies'; moderator for the Sub-Saharan Congenital Anomalies Network 'Webinar Neural Tube Defects in Sub-Saharan Africa'; plenary presentation during the 12th International Conference on Neural Tube Defects in Austin Texas.

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

IF IS A MEMBER OF:

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



eurolinkcat
Health and education outcomes of children across Europe, with congenital anomalies
ONLINE, 7-8 APRIL 2022

Get to know our speakers!



Sine Rissmann, MD, PhD
Sylvia Roosen, PhD

International Conference on Neural Tube Defects
Level and Multi-Partner Engagement



IF HAS AN ONGOING COLLABORATION WITH:

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

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

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

IF COLLABORATES ON PROJECTS WITH:

- Emory University
- European Association of Urology (EAU)
- European Disability Forum (EDF)
- European Network for Independent Living (ENIL)
- European Parliament
- GASPBIF
- Global Alliance for Improved Nutrition (GAIN)
- Governor Kremers Centre-Maastricht University Medical Centre (GKC)
- International Association of Operative Millers (IAOM)
- International Children's Continence Society (ICCS)
- Micronutrient Forum (MNF)
- OMNI-NET Ukraine
- Sub-Saharan Network Congenital Anomalies





COMMUNICATIONS AT A GLANCE

2022 SNAPSHOT

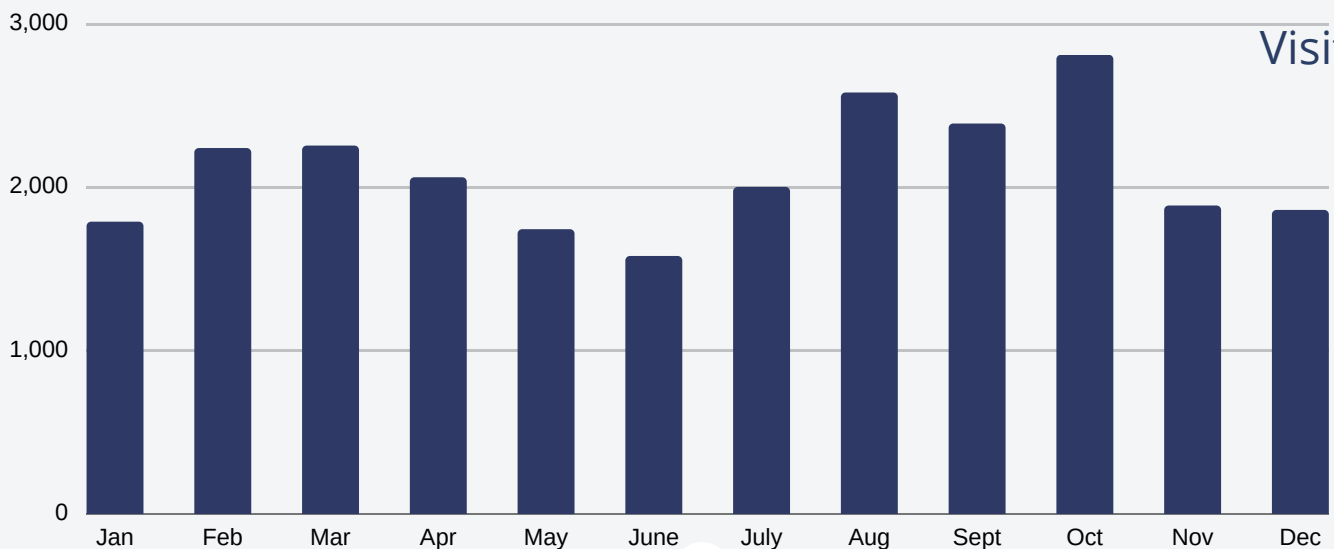
COMMUNICATIONS ACTIVITIES - DATA



Visitors on www.ifglobal.org

25.139

Visitors





“

It is imperative to have the push for change come from the national level and the voices of the SBH community be loud and visible in these actions, thereby advancing the rights and needs of persons with SBH

– Dr Sylvia Roozen
IF Secretary General

CONTACT DETAILS

The International Federation for Spina Bifida and Hydrocephalus

 Cellebroersstraat 16,
1000 Brussels (Belgium)

 +32 (0) 471 84 41 54

 info@ifglobal.org

 www.ifglobal.org

