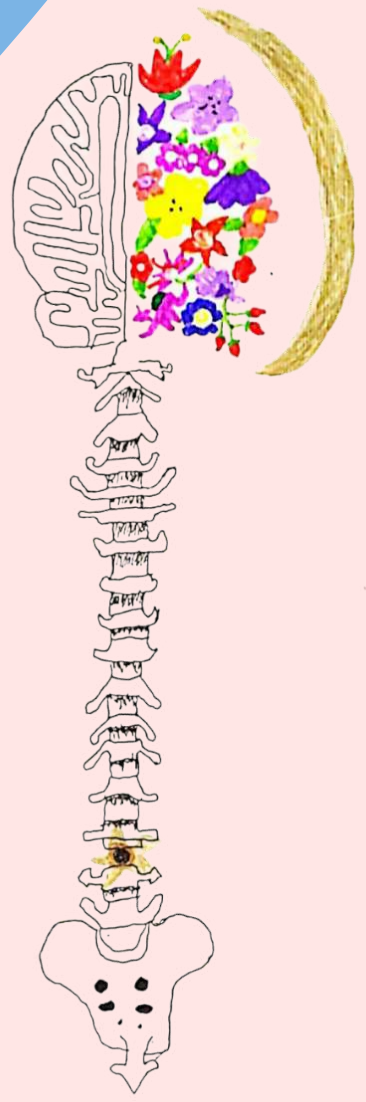




INTERNATIONAL FEDERATION
FOR SPINA BIFIDA
AND HYDROCEPHALUS

ANNUAL REPORT 2021





2022

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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.

The year 2021 was an active one with many activities and challenges. Some of the activities were affected by the COVID-19 pandemic. Therefore, IF organised its activities in a digital format. These activities such as an escape room meeting, training opportunities, international awareness days, and the IF conference for persons with SBH on multidisciplinary care were well-received.

Here, in this annual report 2021, the actions achieved for human rights, primary prevention, optimising management and care, raising awareness, as well as international solidarity are highlighted.

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 exploratory studies, published reports and policy statements, organised opportunities to meet and share experiences, offered training opportunities, and participated as speakers at international events.

For 2021 the concept of twinning was one of the main focuses of attention. Despite the COVID-19 pandemic, twinning opportunities between associations and partners were realised in a creative way.

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

IF looks forward to unlocking potentials together with YOU and also making the next year - 2022 - 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 (IF) is the international organisation representing people with SBH and their families worldwide. IF has country members in Africa, Americas, Asia-Pacific, and Europe with unique and expert knowledge on SBH.

MISSION

The mission of IF is to improve the quality of life of people with SBH and their families, and to reduce the prevalence of neural tube defects 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

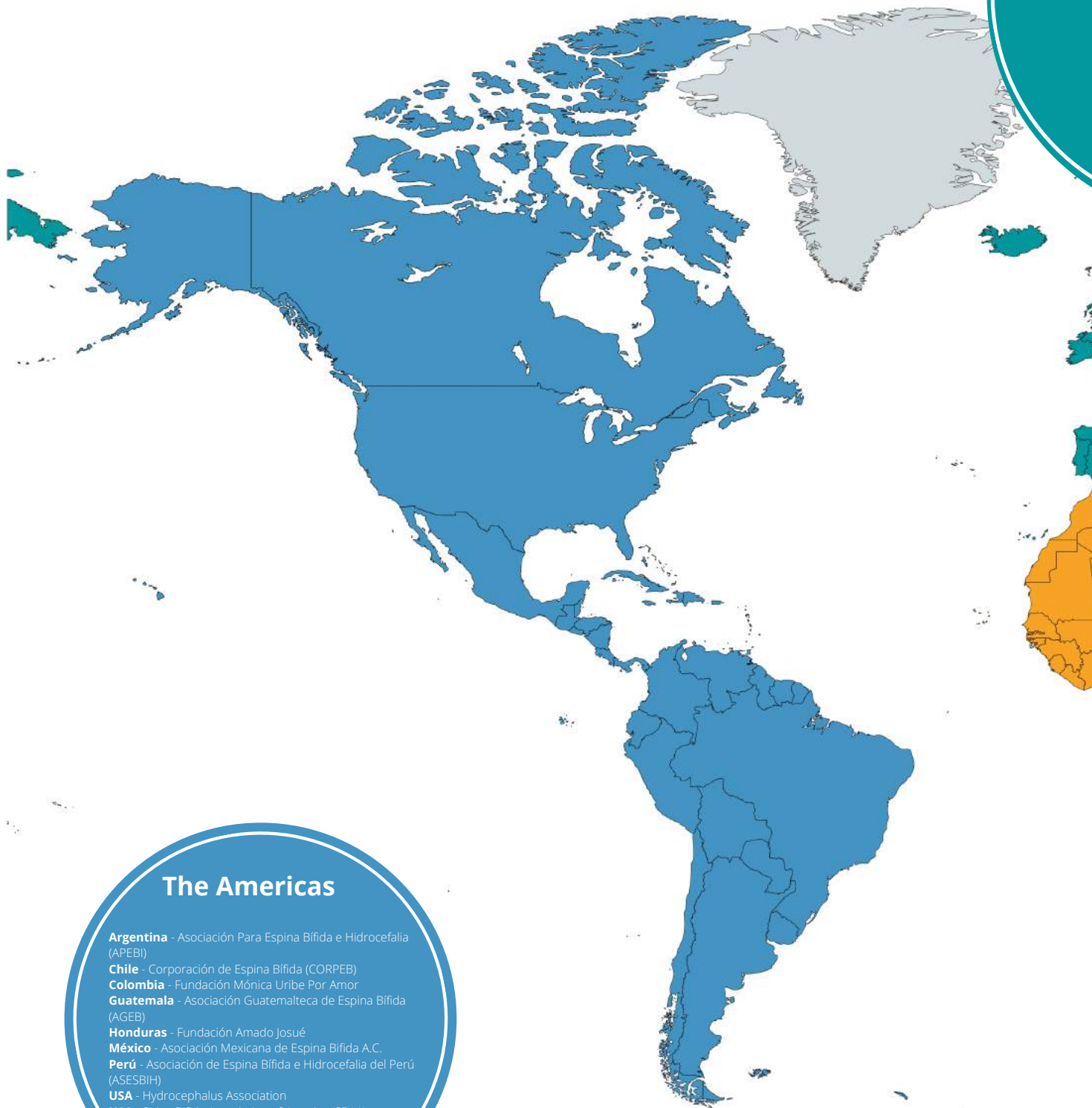
Human Rights: promotion and protection of human rights of people with SBH in accordance with the UN Convention on the Rights of Persons with Disabilities (UNCRPD) is our highest value.

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)
- 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.
- Perú** - Asociación de Espina Bífida e Hidrocefalia del Perú (ASESBIH)
- USA** - Hydrocephalus Association
- USA** - Spina Bífida Association of America (SBAA)

*In 2021, IF welcomed four 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 (SBHB)
Cyprus - Pancyprrian Association of rare genetics diseases 'Unique smiles'*
Denmark - Rygmargbroksforeningen af 1988
Estonia - MTU Eesti Seljaajusonga ja Vesipeahaigete Selts
Finland - Suomen CP-liitto ry
France - Fédération Française des Associations du Spina Bifida (FFASB)
France - Association Nationale Spina Bifida et Handicaps Associés (ASBH)
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 Hydrocephalus Ireland (SBHI)
Israel - Hydrocephalus Israel

Italy - Associazione Spina Bifida Italia (ASBI)

Latvia - Latvijas Spina Bifida un Hidrocefālijas Biedrība (LSBH)

Lithuania - Spina Bifida and Hydrocephalus Association of Lithuania

Luxemburg - Association pour le Spina Bifida (a.s.b.l.)

Montenegro - *Individual representation**

Norway - Ryggmargsbrokk- og Hydrocephalusforeningen

Poland - Fundacja Spina

Portugal - Associação Spina Bifida e Hidrocefalia de Portugal (ASBIHP)

Romania - Asociația Română de Spina Bifida și Hidrocefalie (ARSBH)

Russia - Association of Spina Bifida and Hydrocephalus 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 - Asociación Madrileña de Espina Bifida e Hidrocefalia (AMEB)

Spain - Asociación Murciana de Padres e Hijos con Espina Bifida (AMUPHEB)

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)

The Netherlands - Spina Bifida en 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 - L'Association des Parents et Malades Spina Bifida Béjaïa (APMSBB)
Egypt - Waad Spina Bifida 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)
Uganda - Spina Bifida and Hydrocephalus Association of Uganda (SHA-U)
Uganda - Central Uganda Spina Bifida and Hydrocephalus Network (CU-SBH-NET)
Zambia - Zambia Association for Hydrocephalus and Spina Bifida (ZAHSB)
Zimbabwe - Spina Bifida and Hydrocephalus Association of Zimbabwe

Asia-Pacific

Australia - Spina Bifida Hydrocephalus Queensland (SBH QLD)
China - China Association of Persons with Physical Disabilities
India - Spina Bifida Foundation India
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 representative*
Pakistan - Pakistan Federation For Spina Bifida and Hydrocephalus*
South Korea - Korea Spina Bifida Patient Association (KSBPA)
Taiwan - Taiwan Spinal Bifida Support Society

BOARD OF DIRECTORS



Mrs Elena Monzón de Zappoli
IF President
(until June 2021)
Argentina



Mr Cato Lie
IF President
(from June 2021)
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

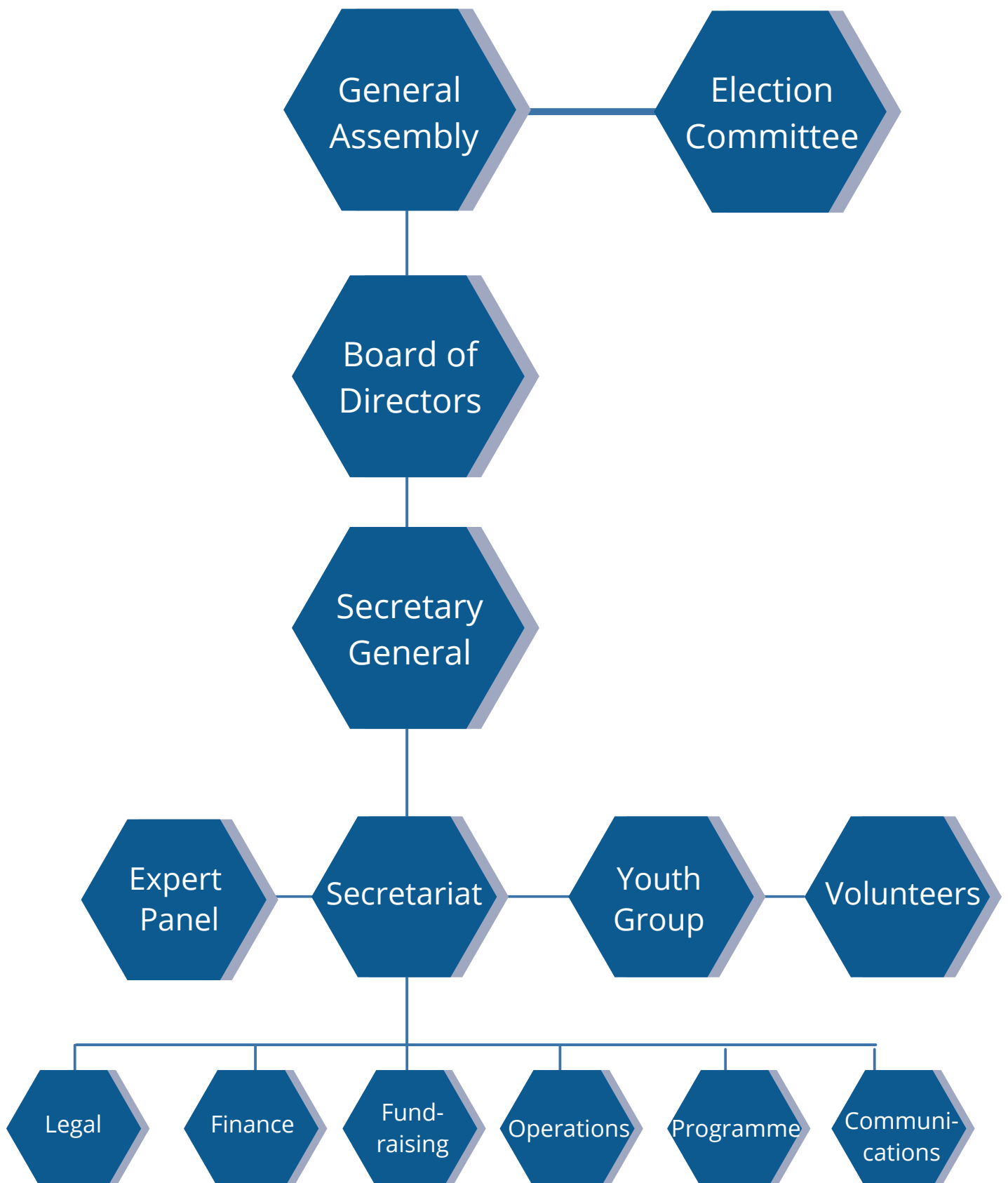
SECRETARY GENERAL



Dr Sylvia Roozen

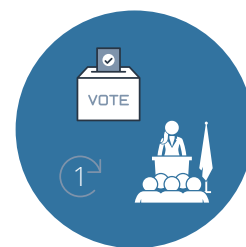
We said goodbye to the outgoing board member and IF president Elena Monzón de Záppoli during the IF General Meeting, June 2021 and welcomed new board members Victoria Sandoval and Sonia Uribe. Cato Lie became the acting president, Victoria Sandoval vice president, Emma Suardiaz treasurer, and Papatya Alkan Genca secretary.

IF ORGANOGRAM



ELECTION COMMITTEE

In 2021, the General Assembly elected the following members for the election committee 2022:



- Dr Margo Whiteford - Spina Bifida Hydrocephalus Scotland (SBHS)
- Dr Aziza Elnaeema - Spina Bifida Federal Association of Sudan
- Dr František Horn - Slovenská spoločnosť pre Spina Bifida a/ alebo Hydrocefalus o.z.

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 2021 the youth group included the following members: Marcus Ward (chair; Ireland), Cillian Dunne (Ireland), Malik Armughan Ali (Pakistan), Parth Hendre (India), Elisa García de Ceca (Spain), Mirela Bukovac (Croatia), Rereloluwa Adeolu (Nigeria), Samuel Opeyemi (Nigeria), Patricia Albertova (Slovakia).

Volunteers

In addition to these advisory groups IF is always fortunate to work with dedicated volunteers. We are particularly grateful in the year 2021 for the support of Li Zhang Chao Yue and Federica Saugo who dedicated their time in support of IF with a video for the World Spina Bifida and Hydrocephalus Day and digital fundraising strategies.

IN MEMORY OF ANNA VERSTER

Much to our sadness, our former colleague Anna Verster (1947-2021) passed away. Anna was a passionate senior advisor for the IF. She was founding mother of Smarter Futures and had worked closely together with IF in public-private-civil partnerships to improve health in Africa through food fortification. Under Anna's leadership, we have come far in making the enrichment of wheat and maize flour a reality in many countries.



Friends and colleagues of Anna will remember her for being a strong and knowledgeable leader in the field of flour fortification and nutrition. She worked as Director of Health Promotion for the World Health Organization – EMR Office in Cairo covering North Africa and the Middle East countries until her retirement from WHO. She was responsible for the introduction of fortification of salt, wheat flour and vegetables in all the countries of the region. Following her retirement, she worked for GAIN before founding Smarter Futures with IF and FFI (Food Fortification Initiative). Determined but always gracious, she was known as 'Mama Lishe', Swahili for Mother Fortification, and throughout her career she has improved the health and lives of over 300 million people in Africa and the Middle East.



Before Anna passed away, she received a special IF Award of Excellence on behalf of IF and the partners of Smarter Futures. A scholarship memorial fund in her name has been created to honour Anna's legacy and stimulate young academics to make fortification with folic acid a reality in countries worldwide.

by IF Secretary General Dr Sylvia Roozen

MAIN ACHIEVEMENTS

Quarter 1 Jan.-Mar.

Awareness Raising

through four international awareness campaign

Community Building

through members meetings in Europe, Africa and Americas region

Advocacy

through 65CSW and 24th session of the committee CRPD

Inauguration

of IF international youth group with SBH

Twinning Opportunities

for women with SBH on equality, motherhood, sexuality

Publications

of the youth report on sexual health

Individual Support

to IF members for their national activities such as the launch of the national patient registry together with ASBI Italy

Partnership Strengthening

with ERN-ITHACA, WHO, RDI, IDA, European Commission

Training Opportunities

for IF members "Connecting with policy makers and using social media for SBH advocacy"; and a training seminar for millers in Egypt together with FFI as part of the Smarter Futures partnership

Publications

of the IF annual report, statement "European Union Strategy for the Rights of Persons with Disabilities 2021 – 2030"

Advocacy

outreach to MEPs following the publication of the IF statement on the new disability strategy; response to the European Disability Strategy

Award

Anna Verster Scholarship

Quarter 2 Apr.-Jun.

Awareness Raising

through four international awareness campaign

Community Building

through members meetings in Africa, Latin-America, Europe region; Smarter Futures partnership meetings; creative writing competition and meeting for and by youth on sexual health in collaboration with IF member Spina Bifida Foundation India

Awareness Raising

through two awareness campaigns

Quarter 3 Jul.-Sept.

Community Building

through IF member meetings, in collaboration with Spina Bifida India Foundation for a webinar on fetal surgery and the India Birth Defects Prevention Task Force

Knowledge Exchange and Twinning

through IF conference for persons with SBH on multidisciplinary care

Publications

of the IF statement on Covid-19; information package on EU and the UNCRPD reporting cycle

Inauguration

of IF as member of the European Commission Disability Platform

Community Building

through members meetings in Europe and Asia region

Training Opportunity

for youth "Human Rights and Advocacy Training - Accessibility in Focus"

Awareness Raising

through four international awareness campaigns

Quarter 4 Oct.-Dec.

Publications

of four IF statements on the EU reporting to CRPD, multidisciplinary care, ageing and sexuality, information package on CRPD; and two reports on mental health by the IF advisory groups on ageing and youth, and the mental health of youth with SBH and Smarter Futures cutsheet

Partnership Strengthening

with EDF, EPR, EASPD

International Solidarity

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

HUMAN RIGHTS

LETTER POLICY OFFICER

The advancement and protection of the human rights of the SBH community permeates all of IF's work. IF policy and advocacy activities in 2021 focussed on raising awareness of the rights and needs of the global SBH community, empowering IF members to further their national advocacy and working together to enact change.

These activities in 2021 resulted in the publications of several IF policy statements. These statements play a vital role in the policy and advocacy work of IF as they outline the challenges facing the SBH community and what IF and its member associations recommend to policy makers and other stakeholders to address those challenges. Some of the 2021 policy statements were published in reaction to external events, for example the COVID-19 pandemic or the European Union (EU) reporting to the Committee on the Rights of Persons with Disabilities. Such statements are an important tool for IF to advocate for the specific needs of the SBH community in context of such developments. Other statements such as ageing with spina bifida and hydrocephalus, on the other hand, were penned in response to feedback from IF members. Such publications contribute to the effort to raise awareness and push these topics higher up on the global political agenda. In these activities IF strives to bring the concerns and priorities from the local and national level to international attention. This is one example of how activities on the national level can have an impact on the international level.

Alongside the policy statements IF published a series of information packages. These information packages were created for IF members to provide them with key concepts of disability rights. Knowledge is empowerment and although today most people can expect to access a huge amount of information and data through a few clicks on the internet, to understand that information in the context of SBH advocacy still remains a challenge. In the IF information packages the IF team focused on providing not only an overview of the topic but also relating it back to national associations and individual activists.

What stands out when looking back at 2021 are the opportunities to interact with members through IF events and training as well as collaborations with the IF working groups for the preparation of policy statements. IF also had the opportunity to raise the visibility of the rights and needs of the SBH community through interactions with policy makers, international organisations and other stakeholders and by speaking at events such as the European Public Health Conference.

The important policy and advocacy work of IF aimed at human rights will be continued.

Hildur Önnudóttir, IF Policy Officer

POLICY STATEMENTS

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

In April 2021 IF published the **“IF Statement on the European Union Strategy for the Rights of Persons with Disabilities 2021-2030.”** The European Union Strategy for the Rights of Persons with Disabilities 2021-2030 (ESRPD) replaces the previous European Disability Strategy 2010-2020 (EDS). In these strategies the European Commission outlines the actions it will take to implement the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). In its statement, IF urged effective implementation of the strategy, especially in those instances where the ESRPD makes promises to mainstream disability rights in all policy areas. This is vital in light of the increased EU activity in health policies.



As the world begins to recover from the COVID-19 crisis there is an urgent need to understand and address how the pandemic has impacted the SBH community. In the **IF Statement on COVID-19**, IF worked with its members to communicate with policy makers on how COVID-19 has affected persons with SBH and what governments must do to address the needs of the SBH community in COVID-19 recovery policies.

The implementation of the UNCRPD is of utmost importance to IF. Acknowledging that the EU is a very important actor for global disability rights and is scheduled to report to the Committee on the Rights of Persons with Disabilities (CRPD) in 2022, IF published a statement on this topic entitled **“IF Statement on EU Reporting to CRPD”**. In this statement IF outlined its recommendations for the reporting process, including areas that must be addressed such as the insufficient mainstreaming of disability rights into all policy areas, including health policies and EU funding programs.



The UN Convention on the Rights of Persons with Disabilities

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) entered into force on the 3rd of May 2008. The UNCRPD outlines the rights of persons with disabilities and the obligations which governments have to uphold and protect those rights.

The UNCRPD was created after decades of work by the United Nations (UN) and disability rights activists who campaigned to transform the attitudes towards persons with disabilities and protect their right to make decisions for themselves and to be included as active members of society. This is achieved through active participation by persons with disabilities and their representative organisations in decision making processes which affect them.



IF, together with the IF working group on ageing with SBH, published the **“IF Statement on Ageing with Spina Bifida and Hydrocephalus.”** The statement builds on the work and previous publications created by IF and the IF working group on ageing with SBH and summarises the key priority issues experienced by members of the SBH community in older age. The statement presents those key issues alongside IF’s recommendations to all stakeholders for actions to improve awareness, knowledge, support, and access to services for older persons with SBH.



Following the International Federation for Spina Bifida and Hydrocephalus Conference on Multidisciplinary Care, IF published the **“IF Statement on Multidisciplinary Care for Spina Bifida and Hydrocephalus”.**



The statement outlines some of the key conclusions from the conference and presents to policy makers and other stakeholders IF’s recommendations to develop and ensure access to quality person-centred multidisciplinary care for all persons with SBH.

Last but certainly not the least, IF worked with the IF international youth group to create and publish an **“IF Statement on Mental, Physical and Sexual Health for Youth with SBH.”** The statement addresses the key challenges identified by youth with SBH and presents the topics of sexual health in a holistic manner together with mental and physical health, acknowledging that these are not separate experiences but rather deeply interconnected factors which contribute to individual wellbeing and societal inclusion.

INFORMATION PACKAGES

IF created information packages to accommodate key policy statements. The information packages are complementary publications created to explain not only how certain processes and policies function in general but also, more crucially, how they work in the context of SBH advocacy.

Three information packages were published in 2021:

- IF Information Package on European Union
- IF Information Package on UNCRPD and the Reporting Cycle
- IF Information Package on the European Strategy for the Rights of Persons with Disabilities

In these information packages IF members can access information on key concepts, institutions, policies, and documents, why they are important for global SBH advocacy, and how national IF member associations and individual activists can get involved and have an impact.



PARTNERSHIPS AND ADVOCACY

Strong partnerships are essential parts of advocacy, and throughout 2021 IF's strong connections were demonstrated through collaborative projects. In June IF contributed two speakers to the EDF workshop on access to health. Furthermore, in November, IF co-organised a side event for the European Public Health Conference entitled "Advocacy for Sexuality Education for Children and Young People with Disabilities". At the workshop IF policy officer contributed as a speaker and gave a presentation on IF's work with youth with SBH on sexuality. In December IF participated in a roundtable discussion at the Online Awareness Raising Event – Challenges and Good Practice Supporting Older People with Disabilities, which was organised by the European Platform for Rehabilitation.



EUROPEAN COMMISSION DISABILITY PLATFORM



IF continued to advocate on key issues within the EU by participating in stakeholder meetings, contributing to public consultations and bringing awareness to the actions being taken, or not being taken on the EU level through social media activity.

In addition, IF became a member of the Disability Platform. This platform is one of the key initiatives outlined in the ESRPD. It is chaired by the European Commission and its members include representatives from the EU Member States and a selection of key civil society organisations, including IF.

The purpose of the platform is to discuss and shape EU policies relevant to disability rights.

AWARENESS RAISING

All IF's activities are rooted in the principles of the UNCRPD and our mission to advance and protect the rights of individuals with SBH. In 2021, IF continued to raise awareness of the rights of individuals with SBH and the UNCRPD among policy makers, relevant stakeholders, and international organisations.

Activities included contributions to consultations, publications of statements and meetings and public awareness campaigns in IF member countries, the EU or worldwide. In particular, the focus was on the priorities indicated by IF members for themes such as mental health and ageing.

INTERNATIONAL AWARENESS DAYS

During 2021, IF held awareness campaigns for thirteen international awareness events: the World Folic Acid Awareness Week; World Birth Defects 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; European Day of Persons with Disabilities; the International Women's Day, the International Day of Families, the World Toilet Day and the International Human Rights Day.

For eight of these international awareness events IF developed social media toolkits to support members and partners in their advocacy efforts.

These toolkits were developed for:

- World Folic Acid Awareness Week
- World Birth Defects Day
- IF's Siblings Day
- International Youth Day
- International Day of Older Persons
- World Mental Health Day
- World Spina Bifida and Hydrocephalus Day (see also page 42)
- International Day of Persons with Disabilities

World Folic Acid Awareness Week



During the week of January 9 to 15 2021, IF celebrated the World Folic Acid Awareness Week (WFAAW). This is an annually recurring week in IF's calendar to focus on additional awareness activities for folic acid and prevention all over the world. 2021 was a special year, marking not only the 5th anniversary of WFAAW, but it also marks the 30 years since the Lancet published an important study highlighting the key role of folic acid in the risk reduction of neural tube defects.

This year's WFAAW event was a great success with the engagement of IF's members, partners, active stakeholders in prevention and individuals from all over the world. Just to highlight the level of engagement, the reach of the campaign activity on Facebook saw an amazing increase of 32,106% on the previous 28 days, and on Twitter the number of daily impressions increased from 350 per day up to 5,186 during the week of the campaign.

Whilst the many unprecedented challenges that we all faced over the past year may have restricted many of the usual 'face-to face' activities and events that we would normally see from IF's members throughout the week, the activity online was greater than IF has ever experienced before, with so many members liking, sharing and commenting on IF's daily posts, and even with social distancing restrictions in place, some members still managed to engage in some face-to-face activities.

IF would like to thank all of the partners and in particular IF's members for being so active in making the WFAAW21 event an online success together.

World Birth Defects Day

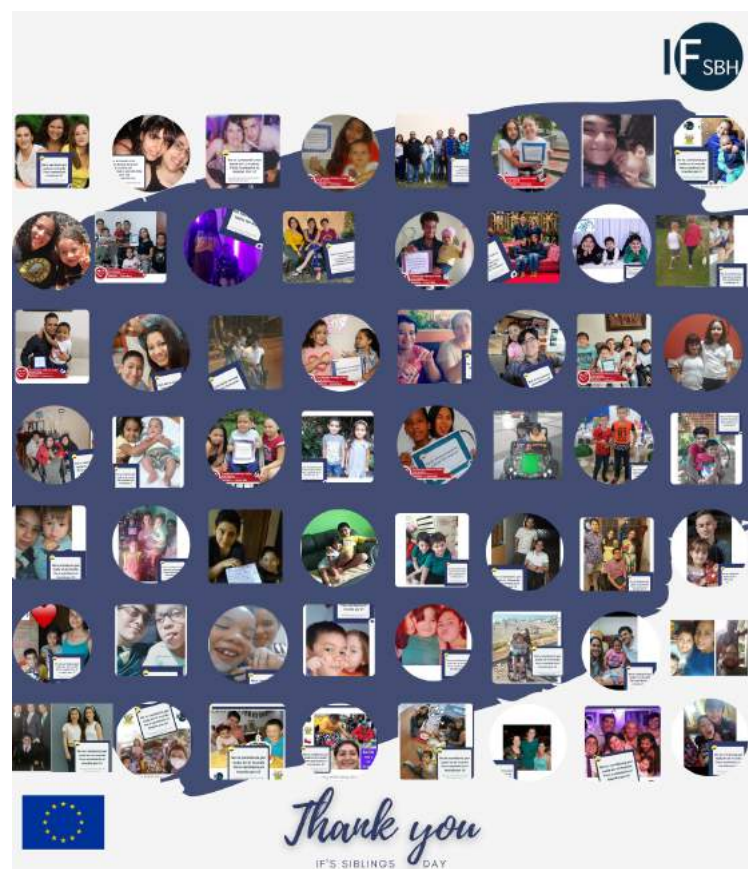


On the occasion of the World Birth Defect Day, IF took part and supported this global movement and day by sharing a social media toolkit to raise awareness of birth defects, including spina bifida and hydrocephalus. Raising awareness is indispensable for spina bifida and hydrocephalus.

This initiative aims at “using our collective voice in raising awareness for all birth defects and improving care and treatment” as it is reported that more than 8 million babies worldwide are born with a birth defect each year.

International Siblings Day

IF organised the first IF's Siblings Day on April 10th. During this day IF honoured siblings with SBH because siblings provide unconditional love and support throughout life: “De mi hermana con espina bífida aprendí que su fuerza de voluntad es mucho más grande que sus limitaciones físicas” (EN: From my sister with spina bifida I learned that her determination is much greater than her physical limitations) (Maria del Rosario Nacim, Argentina). Members around the world shared testimonial stories and lovely images with their siblings. The social media posts showed the strong connections of siblings, including growing up together, complementing each other, supporting and accompanying each other at every moment, teaching each other the different ways of doing the same thing, but on different paths, and always reaching the “arrival” line, perhaps even overcoming thousands of barriers, obstacles or adversities, never giving up, putting all our efforts to achieve it, no matter what it takes.



International Women's Day

Maternal health and empowering women with SBH is of crucial importance 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 furthermore facilitates meaningful discussions between women with spina bifida and hydrocephalus through focus group discussions on topics such as equality, motherhood, and sexuality.



Open Discussion Equality
March 23rd - 3pm (CET)

GUEST SPEAKERS

Ana Sofia Batres Morales
Vivian Lucía Rivera Marroquín
Anđela Radovanović

Open Discussion Motherhood
March 24th - 3pm (CET)

GUEST SPEAKERS

Dilek Nalçakan
Vivian Lucía Rivera Marroquín
Albena Marinova

Open Discussion Motherhood
March 25th - 3pm (CET)

GUEST SPEAKER

Meet Papatya Alkan during our open discussion on **Sexuality** on the 25th of March 2021!

On March 10th, IF celebrated the International Women’s Day to recognise 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. During an online webinar, women around the world shared their stories which inspired others.

“Never give up and always believe in yourself. Because you can find a way to overcome challenges and won't be afraid to ask for help and support. Be the power that can move the world.”

Anđela Radovanović
(Montenegro)

“You have to make big things, it's important to have a purpose in this world and you have to do it. The only barrier is your mind and you think about yourself.”

Ana Sofia Batres Morales
(Guatemala)

“Keep fighting for your dreams, don't give up on your education. We need to have people in different areas to fight for our rights. Everything is possible if you want to do it.”

Vivian Lucía Rivera Marroquín
(Guatemala)

International Youth Day

On 12th of August, IF celebrated the International Youth Day together with its worldwide members and especially with the youth group. This day, designated by the United Nations, is a day of awareness and its goal is to bring attention to a specific set of cultural and legal issues that affect young people.

On this occasion, the IF international youth group chose to address the topical subject of the year: the COVID-19 pandemic! Members of the group shared letters on IF social media channels in which they addressed the many challenges they faced during this tough period.

Through sharing these letters, the youth aimed at a triple objective of raising awareness of the pandemic through the eyes of the youth with SBH, connecting with other youth with SBH around the world to let them know they are not alone and to strengthen the sense of community and solidarity.

through the eyes of a young person w

"Pandemic through the eyes of a young person with SBH"

"Pandemic through the eyes of a young person with SBH"

"Be the change that you wish to see in the world."

"We empower ourselves every time we accept responsibility for choosing the thoughts and feelings we act on."

"Pandemic through the eyes of a young person with SBH"

Malik Armughan Ali:

"We cannot always build the future for our youth, but we can hinder our youth for the future."

"Pandemic through the eyes of a young person with SBH"

through the eyes of a young person w

"We empower ourselves every time we accept responsibility for choosing the thoughts and feelings we act on."

Happy Youth INTERNATIONAL DAY

INTERNATIONAL FEDERATION FOR SPINA, BEIGA AND HYDROCEPHALUS



World Mental Health Day

On October 10th, IF celebrated the World Mental Health Day to raise awareness on mental illnesses. Supported by WHO, on this international day the world takes the opportunity for global mental health education, to raise awareness for and to advocate against social stigma. This is also an important topic for IF. Both the working group on Ageing with SBH and the youth group highlighted the important role of mental

health on physical well-being and how mental health affects physical well-being. During this day a social media toolkit was developed and shared with members and partners to provide more information on mental health for persons with SBH.



International Day of Older Persons

On October 1st, IF took the opportunity to raise awareness on ageing with SBH, the barriers older persons with SBH can face, and the need for lifting these barriers. During this day, IF emphasised the importance of integrated care for persons ageing with SBH and the fact that individuals with SBH are subject to “accelerated ageing” which means the ageing process for

some groups of people with disabilities begins earlier than usual, such as for individuals with SBH.



International and European Days of Persons with Disabilities

On the days of 2 to 3 of December 2021, IF joined both the International and European days of persons with disabilities.

During these days, IF advocated for the rights of persons with disabilities, especially to raise awareness on SBH through a social media campaign and toolkit. SBH is a complex physical condition that touches many aspects of the lives of individuals with SBH, sensitises about disability inclusion and speaks up about their challenges and their need to help the SBH community to go forward and be heard.



On the European Days of Persons with Disabilities (December 2-3), the point of focus was the topics of access to healthcare and digital transformation, especially since the COVID-19 pandemic exacerbated these. Moreover, on this occasion, the IF international youth group and the EDF youth committee e-collaborated to send strong messages about access to healthcare, digital transformation, and children with disabilities. They also highlighted the situation of thousands of young people in Europe such as youth with disabilities who are at greater risk than other groups by calling the European Commission to dedicate the European Day of Persons with Disabilities in 2022 to young people to celebrate the European Year of Youth.

PREVENTION

PRIMARY PREVENTION

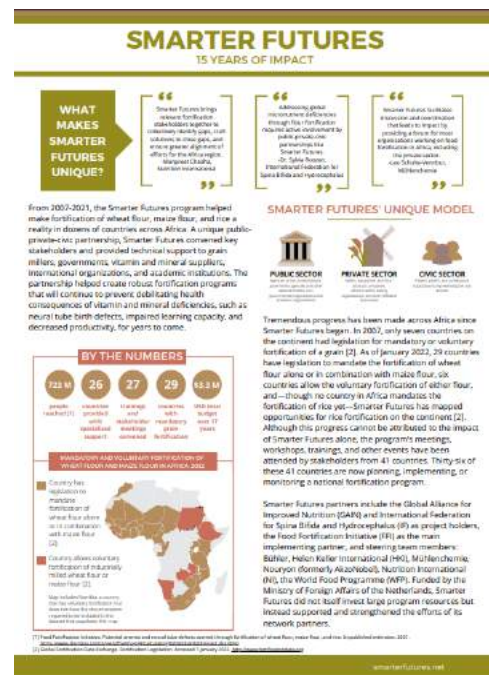
As project holder of Smarter Futures and key partner, IF is driven by its mission to decrease the birth prevalence of spina bifida and hydrocephalus through primary prevention measures and to improve the quality of life for those living with these disabilities. IF represents over 80 Member Associations worldwide of which 14 are located in Africa, notably Algeria, Egypt, Ethiopia, Ghana, Kenya, Malawi, Morocco, Nigeria, South Africa, Sudan, Tanzania, Uganda, Zambia and Zimbabwe. These associations, healthcare professionals, and other interested partners provide advocacy, primary and secondary prevention activities in the countries where they are based.

Between 2007-2021, Smarter Futures¹ has worked together with flour millers, governments, vitamin and mineral suppliers, international organisations, and academic institutions to make fortification of wheat and maize flour a reality in Africa. This public-private-civic partnership is also called Smarter Futures.

Smarter Futures brings together the milling industry, governments, and development partners to support the implementation of national flour fortification programs and aims to improve the nutritional quality of wheat and maize flour in Africa. We do this by providing training to millers, regulatory inspectors, program managers, and regional and international agencies on quality assurance and quality control, monitoring and surveillance, cost-benefit analyses, and fortification advocacy. This is of course relevant not only for Africa but can also be applied elsewhere.

The success of Smarter Futures has been significant. Over the first 15 years of Smarter Futures' existence, 41 countries in Africa have participated in its workshops, trainings, meetings, and other events. Of these countries, 29 (70% of all countries in Africa) now have legislation to mandate the fortification of wheat flour alone or in combination with maize flour, while another six countries allow the voluntary fortification of either flour, and – though no country in Africa mandates the fortification of rice yet, we mapped opportunities for rice fortification. Six countries do not (yet) have fortification, but about half of them are planning to do so in the near future.

Tremendous progress has been made across Africa since Smarter Futures began. Read the report to learn more about Smarter Futures 15 years of impact here².



1. Smarter Futures website. <https://www.smarterfutures.net/>

2. Food Fortification Network, the International Federation for Spina Bifida and Hydrocephalus (2021). *Smarter Futures 15 years of impact*. <https://www.ifglobal.org/wp-content/uploads/2022/02/Smarter-Futures-15-Year-Summary-210128.pdf>

MANAGEMENT AND CARE

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 2021 our regular meetings for the ERN-ITHACA working group spina bifida focussed on strengthening visibility of IF member associations and service providers with opportunities for mutual learning exchanges. In addition, IF facilitated the co-production of guidelines on urological management for children and adults with spina bifida in cooperation with ERN eUROGEN (the ERN for rare urogenital diseases and complex conditions in both children and adults).



PATIENT REGISTRY

On an international level, joint action plans have been carried out to develop partnerships and strengthen infrastructures to improve multidisciplinary healthcare, evidence-based management, and collection of secure patient data. Patient registries can significantly contribute to enhancing existing knowledge and characterization of individuals with spina bifida and/or hydrocephalus. Patient registries moreover provide an important source of data for surveillance which can also inform scientific, clinical, and policy. Besides our current understanding on the important topic of patient data, it is also meaningful to take into account possible factors prohibiting effective integrative approaches on a national level. Analysing interactions between science, practice, and policy is therefore of utmost importance.

A particular highlight was the collaboration with the Associazione Spina Bifida Italia (ASBI), the European Medicines Agency (EMA), and the Italian Ministry, IF organised an online webinar titled “Patient Registries for Spina Bifida and Hydrocephalus” for clinicians, policy makers, representatives of Italian associations of spina bifida, individuals with SBH and family members. During this meeting speakers were invited from the Italian Ministry, the European Medicines Agency (EMA), and EUROlinkCAT. The session was moderated by IF Secretary General and Prof dr Giovanni Mosiello, co-chair of the ERN-ITHACA working group spina bifida.

The meeting was opened by the IF Secretary General and President of ASBI. Both highlighted the need for a joint action plan to improve infrastructure for multidisciplinary healthcare, evidence-based management and accurate and secure data collection patients on a European level. Speakers shared unique perspectives to patient registries and the need for improvement. Dr Kelly Plueschke of the European Medicines Agency (EMA) who shared EMA's involvement in establishing patient registries. Dr Amanda Neville of EUROlinkCAT together with Dr Elena Marcus of the Population Health Research Institute who shared experiences on linkage data through the network and activities by EUROCAT. Prof. Dr Anna Latos-Bielenska of the Department of Genetics at the University of Poznan presented the process of setting up the Polish Register of Congenital Malformations as an example for Poland. Dr Domenica Taruscio, Director of the National Center for Rare Disease (CNMR) presented the Italian project on the Research Registry and how the scientific and clinical studies on spina bifida illustrated the path that led to its establishment. An inspiring testimony by a person with spina bifida was shared by Dr Eleonora Giannetti, member of the Group Giovani ASBI, who spoke as a patient but also as a psychologist.

The last speaker of the webinar was Dr Tiziana Redaelli, doctor at the Niguarda hospital in Milan and member of the Scientific Committee for the creation of the Italian Registry, who examined the clinical and organisational implications of the registry.

The Italian patient registry was an example of twinning to inspire the work undertaken in other countries. Such a registry will allow the pursuit of the purpose of prevention, diagnosis, treatment, health planning, verification of the quality of care and the evaluation of health care.



**WEBINAR PATIENT
REGISTRIES SPINA BIFIDA
AND HYDROCEPHALUS**

PROMOTED BY   INTERNATIONAL FEDERATION
FOR SPINA BIFIDA
AND HYDROCEPHALUS

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JUNE 16, 2021
9.15 - 12.15 (CEST)
ONLINE ON ZOOM UPON REGISTRATION

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FOLLOW US ON OUR SOCIAL MEDIA 

THE INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS CONFERENCE ON MULTIDISCIPLINARY CARE

One of the highlights in the year 2021 was that our federation organised the first online international conference for people with SBH on multidisciplinary care (taking place from September 14 to 17 2021).

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 five keynote lectures, 33 talks, and eight sessions was a great success.

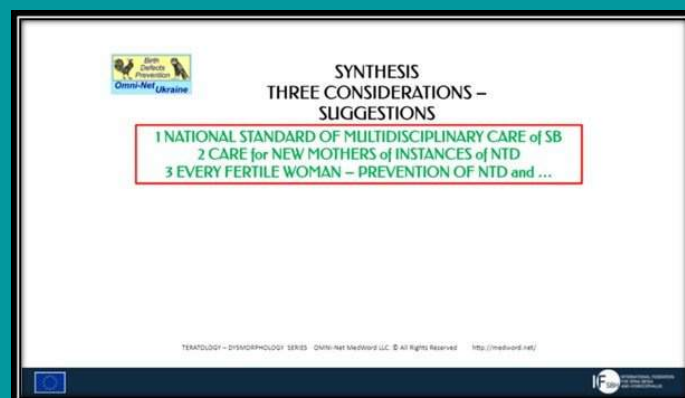


After the welcoming words of the IF president Cato Lie and the IF Secretary General and congress chair Dr Sylvia Roozen, this four-day conference started with an inspiring opening lecture by Prof Dr Wladimir Wiertelcki (Ukrainian-American physician and Emeritus Professor; director of OMNI-Net) – ‘Spina Bifida Care – In Ideal, in Practice and in Reality’. In his keynote, Prof Dr Wiertelcki emphasised on prevention being the best care and the need to work towards standards of care. His presentation set the scene for the coming days. Three considerations were shared with the audience reflecting suggestions for the way forward:

1) the importance of a national standard of multidisciplinary care of SB

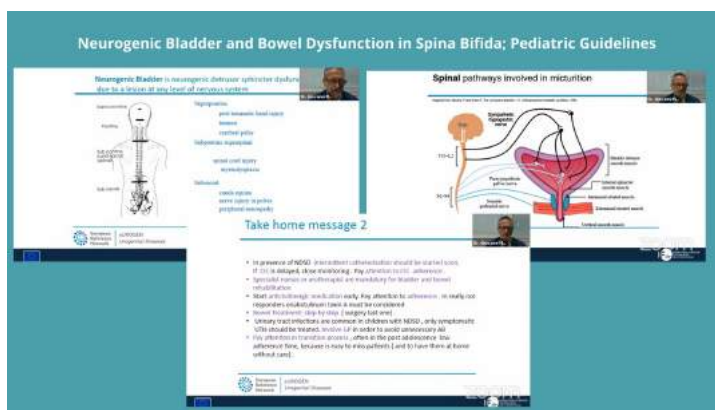
2) care for mothers and families immediately after being informed of Neural Tube Defects during pregnancy or after birth

3) prevention measures for women of child-bearing age.



On the second day of the conference, we were treated to two keynote lectures. One presentation given by Dr Giovanni Mosiello, head of the Clinical and Research Unit of Pediatric Neuro-Urology Unit, Department of Surgery at the Bambino Gesù Children’s Hospital and Research Institute Rome, Italy; and one by Dr Andrea Manunta, consultant adult urologist, Centre de Référence Spina Bifida - Spinal Dysraphisms in Rennes University Hospital, France respectively co-chair and chair of the ERN-ITHACA working group spina bifida.

Dr Mosiello underlined the importance of paediatric guidelines related to neurogenic bladder and bowel dysfunction. In his lecture, he emphasised the importance of further adapting and developing of neurogenic bladder and bowel dysfunction guidelines for individuals with spina bifida, what to do to recognise it, and best possible management and treatment procedures.

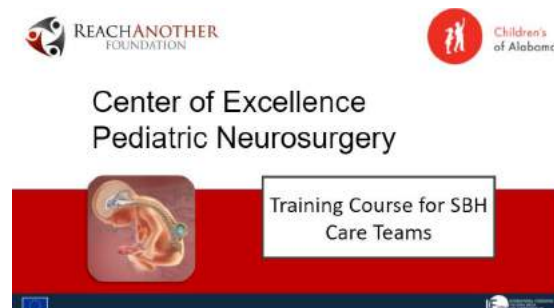


Dr Manunta presented on urological management for adults with spina bifida. In line with the keynote presentation by Dr Mosiello, Dr Manunta emphasised the need for guidelines to support evidence-based and medical decisions about the care of individuals with spina bifida. Existing guidelines on neuro-urology and urological management for both children and adults do exist, however, these are very general on all aspects of care for individuals with Spina Bifida at all ages. Therefore, together with Dr Giovanni Mosiello and IF, the ERN-ITHACA working group spina bifida focusses on European guidelines on urological management of spinal dysraphism.



Dr Mosiello and Dr Manunta emphasised that guidelines can replace neither medical expertise nor multidisciplinary care. The field is complex with significant gaps in our knowledge. Both keynote speakers pointed at the importance of further research on neuro-urology and urological management in order to respond, as well as possible, to the needs of people with spina bifida.

During the last day of the conference Dr Marinus Koning, founder of the Reach Another Foundation, Ethiopia provided a keynote lecture on 'Building Capacity for Spina Bifida and Hydrocephalus Care in Ethiopia, a 12 Year Perspective, Lessons Learned and a Way Forward'. His presented journey showed the establishments of collaborations, centres of excellence for paediatric neurosurgery with multi-disciplinary SBH care teams, and the challenges of providing care in Ethiopia. Dr Koning clarified how ambitious goals with limited resources were achieved. Dr Koning together with his twin brother are now working towards a new challenge of high-risk prevention and the routes of food fortification to ensure new-born health in Ethiopia.



The final keynote lecture was presented by Dr Santosh Karmarkar, senior consultant pediatric surgeon, at the department of Pediatric Surgery, at Lilavati Hospital and Research Centre Bandra Reclamation, Bandra West in Mumbai, India; founder trustee of the Spina Bifida Foundation India. Dr Karmarkar gave in his inspiring lecture an overview of the many players involved in multidisciplinary care for individuals with SBH and their families. He presented a journey of over 25 years as a doctor treating individuals with spina bifida and made a comparison with music.



The multidisciplinary care for individuals with SBH as well as their families requires a full orchestra of 'key musicians' such as the urologist, fetal surgeon, nurse, and other disciplines. Integrated care, similar to a good musical concert, requires the determination of a conductor who has both the knowledge of each instrument and can bring the multidisciplinary orchestra together to provide optimal care. Dr Karmarkar shared the suggestion to also be aware of the missing players in those centres providing multidisciplinary care and to pay close attention to the accessibility of care for individuals with SBH as well as their families.



Programme Book
14th - 17th September 2021

In the words of the last keynote of Dr Santosh Karmarkar "Each one of us has an important role to play to improve cure and care. This week we have experienced the importance of the conversations and dialogues on very fundamental issues to practical applications for our work".

The presentations during the eight conference sessions by the many speakers around the world have shown the importance of stimulating the process of reflection on multidisciplinary care related to SBH. The speakers gave an extra impulse and provided additional impetus for the process of multidisciplinary care. The conference also highlighted that more practical revenues can be achieved for the different teams in the different countries.

During the conference many inspiring examples were given by the speakers for starting this dialogue among others by the IF working group on ageing and the international youth group. However, more can be achieved and based upon this inspiring conference IF will continue facilitating dialogues for fruitful learning experiences, exchange of knowledge and implementation of knowledge and practices. In particular IF will further facilitate the 'twinning' aimed at good practices exchange and connect research and innovations on multidisciplinary care between countries.

COMMUNITY BUILDING

For community building, IF organised regional member meetings with the boards of IF member associations in Africa, Asia-Pacific, Europe, Latin-America. Moreover, the members of the IF working groups on ageing, youth, women with SBH, and multidisciplinary care continued their activities in raising awareness on topics relevant to these working groups. In addition, exploratory studies were conducted, and several meetings were organised to share experiences and provide training opportunities, as well as influencing policy through publications of statements and speaking at international events.

In the year 2021 special attention was paid to the concept of twinning. IF facilitated ‘twinning’ meetings aimed at good practices exchange and connect research and innovations on multidisciplinary care between countries.

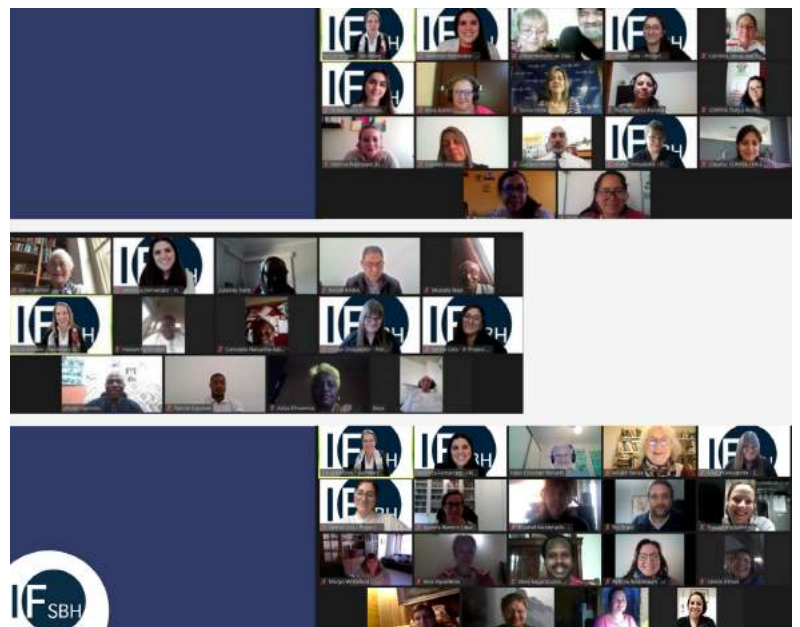
While the COVID-19 pandemic prevented IF from organising in-person meetings, there were several opportunities where members initiated joint actions and moments where IF facilitated twinning opportunities between associations and partners on country level.

IF ACTIVITIES MEMBERS

WEBINARS

The IF member associations, individuals with SBH and their families are at the core of IF organisation activities. In 2021, members participated in online dialogues, training opportunities, awareness raising activities, workshops, and peer support groups. With an ageing population, adults with SBH and their specific needs and concerns are becoming a focal point as well.

Following the outcomes of 2020, IF continued to professionalise its digital ways to connect with members from all over the world.



During IF member meetings with presidents of members associations from Africa, Americas, Asia-Pacific, and Europe, needs were assessed that informed IF's work on advocacy, policy, primary prevention, and improvement of care.

For IF members in the African region, actions and opportunities were shared on primary prevention, advocacy and food fortification. Upon request of members, IF followed-up with specific training opportunities to strengthen national advocacy. Together



with members of the Latin-American network on SBH, the meetings had a strong focus on networking and engagement during international awareness events. Moreover, a new regional network was established together with the Spina Bifida Foundation India for partners in the South Asian network. In these meetings, steps are explored to bolster the work on prevention and improvement of management and care for individuals with SBH and their families. Depending on the interest and needs by members and partners, these regional meetings will be continued in the subsequent years to further strengthen the work on national and regional levels.

TRAINING

In April, IF organised an IF members training entitled “Connecting with Policy Makers and Using Social Media for SBH Advocacy”. The training was a great success, the IF team presented to participants tips and advice for maximising the efficacy of their outreach to policy makers, and the general public. During the interactive session participants were also able to discuss with the IF team specific questions and concerns that they encounter when conducting SBH advocacy on the national level.



COUNTRY-SPECIFIC TRAININGS FOR CIVIL SOCIETY ORGANISATIONS TO CREATE DEMAND FOR FORTIFIED PRODUCTS

IF member associations are the most important advocates to make flour fortification a reality in countries worldwide.



Dr Quentin Johnson
Food Fortification Consultant

To strengthen the advocacy work on the importance and cost-benefits of fortification, IF organised a training with invited speaker Dr Quentin Johnson, food fortification consultant to strengthen member associations expanding national advocacy through a more active involvement of civil society in advocacy and monitoring. Dr Johnson shared his unique and longstanding experiences with millers, governmental officials, and other relevant stakeholders involved in fortification. He emphasised the important role of parental support groups to make fortification a reality. Members shared their examples within countries to advocate for primary prevention.

The meeting was particularly an opportunity for IF member associations to ask and receive information on food fortification on a national level.

TWINNING

Together with IF member associations, several initiatives were created to allow for twinning opportunities between associations, across countries. Some highlights included programs launched on a national level to stimulate collaborations between parent organisations and healthcare professionals. With the support of IF, Italy launched their first national patient registry for SBH and the launch of a national prevention campaign.

In 2021, the parent association for Spina Bifida and Hydrocephalus 'Lights of Spirit' in Ukraine organised a successful series of webinars.



The 'Fundacja Spina' launched their SOS programme to build a support network for families in Poland.

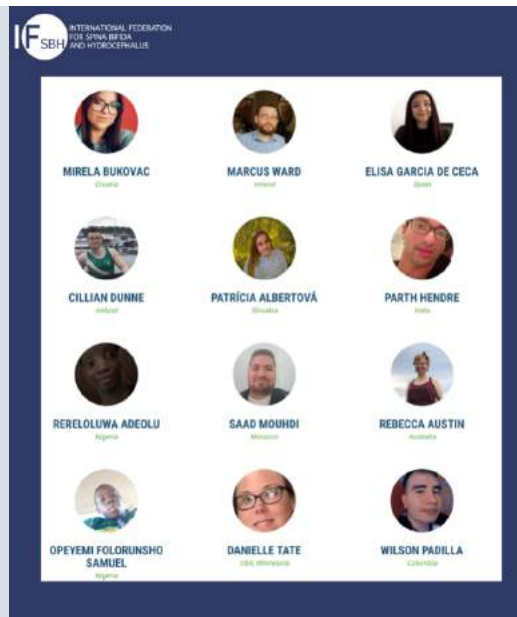


Also other initiatives highlighted the need for standards of care, such as the launch of the programme by Spina Bifida Association Malaysia (SIBIAM). In 2021, there was a very productive collaboration with the Spina Bifida Foundation India. India organised several important events such as the webinar on fetal surgery. The speakers were Dr Agnieszka Pastuszka, Dr Anita Olejek coordinated by Dr Santosh Karmarkar with closing remarks by Mr. Rohit Shelatkar.



ACTIVITIES IF ADVISORY GROUPS

YOUTH GROUP



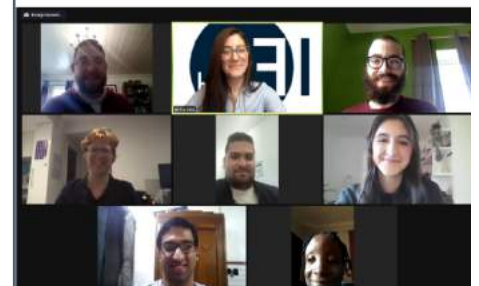
MEETINGS

The youth group SBH represented a total of 11 young persons with SBH, 5 males and 6 females aged 18 to 28 years from countries around the world. During online meetings they discussed ways to address important issues relevant for them. The youth emphasized mental, physical, and sexual health. Dialogues took place on different levels.



TRAININGS

IF organised the training titled “Human Rights and Advocacy Training for Youth with SBH – Accessibility in focus”. This training consisted of several small-interactive sessions which provided youth with an opportunity to further their skills and understanding of disability rights and advocacy, and to connect with individuals across countries who are facing similar situations.



During the training participants (i) learned about the UN Convention on the Rights of Persons with Disabilities, (ii) connected and learned from experienced professionals in the field of advocacy, (iii) joined and connected with other youth with SBH, (iv) explored the important topics of accessibility, the right to health and using social media for SBH advocacy.

IF HUMAN RIGHTS AND ADVOCACY TRAINING FOR YOUTH WITH SBH - ACCESSIBILITY IN FOCUS

November 8th - 9th | 4pm - 5.30pm
 November 15th | 4pm - 6.30pm
 November 16th | 4pm - 5.30pm
 (Hours in CET)



KNOWLEDGE GATHERING

This year the members of the IF international youth group with SBH focussed on the impact of the COVID-19 pandemic on mental health. To better understand the needs and experiences of youth with SBH, the youth group developed an online survey to explore challenges related to mental, physical, and sexual health.

PUBLICATIONS

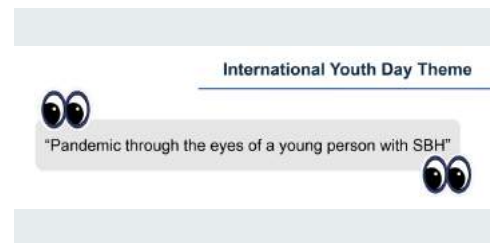
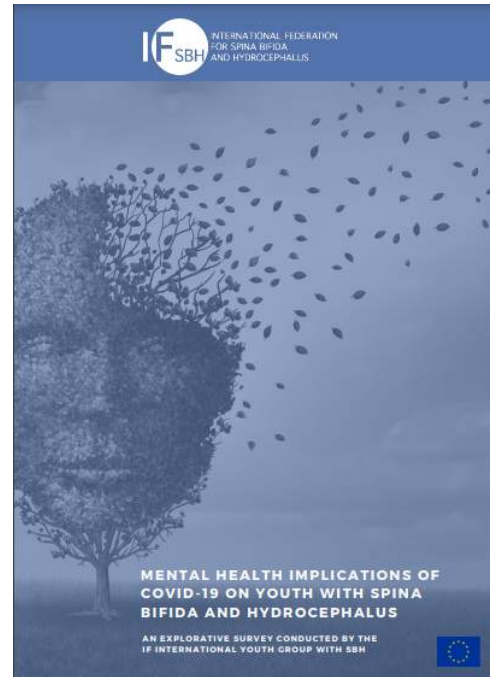
The knowledge gathering activities were documented in the report “Mental Health Implications of COVID-19 on Youth with Spina Bifida and Hydrocephalus”. In an addition, a policy statement was published on mental, physical and sexual health for youth with SBH. This statement describes challenges that persons with SBH encounter with regards to mental, physical and sexual health as well as IF’s recommendations for advancing the rights and wellbeing of persons with SBH on these issues.

VISIBILITY

During the International Federation Conference for people with SBH on multidisciplinary care, Marcus Ward (chair of the youth group SBH) shared the outcomes of the explorative study on mental health.

The IF international youth group with SBH has also been very visible on social media. During the International Youth Day, the youth created a toolkit and challenged members to take part in their online “Pandemic through the eyes of a young person with SBH” challenge, which was a great success!

For the occasion of the World Mental Health Day, the international youth group explored ways to engage with members. During the preparation for this day, the youth developed a survey and asked young people around the world to share their experiences with mental, physical, and sexual health. For this particular day, a special social media toolkit was developed to gather personal testimonies and invite members to raise awareness, share their experiences, thoughts and views on mental health.



During the WSBHD21, the group organised a youth-only side event called “digital escape room” in the theme of the WSBHD21 “Unlock Your Right to Health”. Young people from around the world engaged in this meeting and tried to solve a series of clues to ‘escape from the room’ working in smaller groups. The first of which to find all the clues was declared the winners of the digital escape room event.

The youth group also collaborated with different youth groups around the world. One of the meetings took place in collaboration with the youth group of Spina Bifida Foundation India titled “Sexuality and Psychosexual Concerns in Spina Bifida”. On the occasion of the European Day of Persons with Disabilities 2021, the IF international youth group SBH and the EDF youth committee worked together to celebrate the European Day of Persons with Disabilities.



In this e-collaboration, the call was made on the European Commission to dedicate the European Day of Persons with Disabilities in 2022 to young people to celebrate the European year of youth.



WORKING GROUP AGEING

MEETINGS

The working group on ageing continued their meetings to discuss ways to improve our understanding of the lived experiences of older persons with SBH. This year the key topic was on multidisciplinary care.

KNOWLEDGE GATHERING

The working group organised online focus group discussions, open to all persons with SBH across the world. Discussions from the focus groups reflected the importance of ageing with a specific attention for mental and physical health, and they were published.

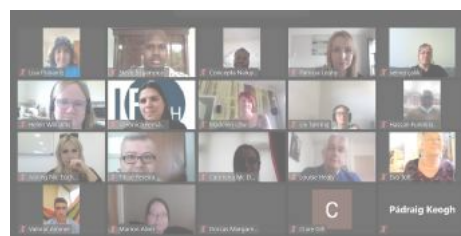
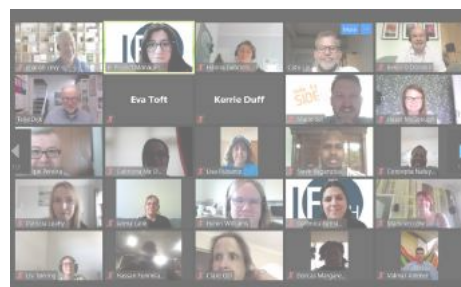
PUBLICATIONS

The online focus groups' discussions were published in the report titled "Ageing with Spina Bifida and Hydrocephalus – Findings from Online Focus Group Discussions".

Moreover, the working group provided input for the IF statement on ageing which outlines recommendations to advance and safeguard the rights of individuals experiencing ageing with SBH, to support the development of appropriate services such as multidisciplinary care and person-centred social care.

VISIBILITY

The IF working group on ageing with SBH organised two webinars to bring persons with SBH in contact with each other and to share experiences on the topic of ageing. The focus of the first webinar was mental and physical health. Members shared several ageing-related challenges such as loneliness, social isolation, physical pain, mental constraints and feeling of depression, perceived stigma, the need for support groups, and the importance of coordinated multidisciplinary care.



The second webinar was a side event “Ageing Well with Spina Bifida and Hydrocephalus” to celebrate the World Spina Bifida and Hydrocephalus Day.

Speakers from different parts of the world shared their experiences on aspects such as the need for support networks, the importance of multidisciplinary healthcare systems, and example experiences of rehabilitation centres. These open dialogues were well received by participants and the IF working group on ageing with SBH will continue for the next years to organise future opportunities for people to meet and develop actions on the important topic of ageing.



WORKING GROUP ON MULTIDISCIPLINARY CARE

MEETINGS

The working group on multidisciplinary care focussed within her subgroups on contributing to the important event of the International Federation for Spina Bifida and Hydrocephalus Conference on Multidisciplinary Care 2021.

KNOWLEDGE GATHERING

In order to support IF members’ efforts to bring the most appropriate care and support to persons with SBH in their countries, the IF working group on multidisciplinary care has conducted an explorative study on the best practices examples of multidisciplinary care in Europe. The study results have formed the basis for a report on the principles for multidisciplinary for people living with SBH.

PUBLICATIONS

Results from the explorative study on best practices were published in the report “Multidisciplinary Care for Individuals with Spina Bifida and Hydrocephalus in Europe”. The outcomes of the IF working group on multidisciplinary care also informed the publication of an IF statement emphasising that the highest attainable standard of health for persons with SBH cannot be achieved without multidisciplinary care.

VISIBILITY

Although there exist different models of multidisciplinary care teams bringing together medical, paramedical and social care professionals, there is not yet a clear standard on what adequate multidisciplinary care for SBH should encompass in different contexts (high/low-income countries, large/small countries, socioeconomic and demographic factors, etc). Moreover, in Europe, there is a remarkably large divide between Northern/Western European countries and Central/Eastern countries in access to multidisciplinary care. These were the topics for the International Federation for Spina Bifida and Hydrocephalus Conference on Multidisciplinary Care 2021. The members of the working group presented their country updates as discussed in their subgroups.



WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY

The World Spina Bifida and Hydrocephalus Day (WSBHD21), taking place on October 25, 2021, was an inspiring moment of celebrating and sharing information about Spina Bifida and Hydrocephalus across countries and continents both digital and in-person. The theme of this year was “Unlock Your Right to Health”.

On this day, IF together with her worldwide members led an impactful awareness raising campaign on social media. IF launched a testimonial challenge and you can see the video on IF YouTube channels (<https://www.youtube.com/user/IFglobalorg>). Moreover, IF organised a main conference and several side events also together with IF members.



In addition, IF members organised specific activities such as other campaigns on social media, advocacy towards national parliaments, musical concerts, and local conferences in collaboration with healthcare professionals and other experts.

CONFERENCE UNLOCK YOUR RIGHT TO HEALTH

For the occasion of the World Spina Bifida and Hydrocephalus Day 2021, IF organised as the main event a conference ‘Unlock your Right to Health’ (see [here](#)).

This conference was opened by the IF President Cato Lie who highlighted the UNCRPD which states that people with disabilities have the right to the highest attainable standard of health as per article 25. He also pointed out the importance of protecting the rights of individuals with SBH and called worldwide actors to: “Unlock Your Right to Health”. Subsequently, the IF Secretary General Dr Sylvia Roozen, chair of this main event, emphasised October as the SBH awareness month. She also pointed out the importance of advocating and promoting the rights of persons with SBH while underlining the strengths of the SBH community in reaching these goals.

Guest speakers

Dr Santosh Karmarkar
SBH India

Ruth Nalugya
SBH Uganda

Elena Zappoli
APEC Argentina

Andrej Drdul
SBH Croatia

MAIN EVENT

OCT. 25
3PM-4.30PM (CEST)

For more info visit: <https://www.worldspinabifidahydrocephalusday.com/>



Dr Santosh Karmarkar (Convener and Trustee, Spina Bifida Foundation, India) was the first speaker. Dr Karmarkar continued his inspiring lecture during the IF conference for people with SBH on multidisciplinary care and emphasised again in an uplifting way the importance of collaboration of the representatives of the different involved disciplines for realising good care for patients with SBH.

The second guest speaker of the conference was Ruth Nalugya (President of SHA-U, Uganda) who expanded on community building to unlock the right to health. She shared with us how SHAU-U raised awareness in many creative ways with the inspiring example of an anthem. For this special day, SHA-U released a beautiful and touching spina bifida anthem sung by Kerstin Blessing, a 9-year-old girl with SBH. The anthem is available [here](#).



In the next presentation of Dr Federico Nuñez Perea (President of RENAPRED and RELAPRED, Mexico) and Elena Záppoli (President APEBI Argentina, chair RELAEBHI) illustrated and stressed the importance of the large RELAEBHI network among Latin American countries. This network was initiated by IF Member Association APEBI in Argentina to support communities in Latin America.

This community is made up of individuals with SBH, friends, families, healthcare professionals, politicians and sponsors, and they work on spreading awareness about the rights of persons with SBH.

The last but not least speaker of the day was Andrej Drdul (Co-founder and board member of the SBAH, Slovakia) who covered the concept of twinning experiences. He presented various twinning experiences - which means taking example on other organisations - between national disability associations across countries and continents. Andrej Drdul gave an overview of different kinds of twinning such as summer camps for children with disabilities where children can connect and discover about other children with disabilities similar or different than themselves.

To conclude, perspectives on this year's theme "Unlock your Right to Health" through different angles were shared. We learned about the need of an orchestra consisting of many players; community building through a very special musical contribution; the need for networking across countries; and how countries can support other countries through the concept of twinning.

WSBHD21 SIDE EVENTS

DRAWING CONTEST

As part of the World Spina Bifida and Hydrocephalus Day activities, a drawing contest was launched on the topic of the WSBHD21 “Unlock your Right to Health”. It was wonderful to see the many talented drawings received by persons and children with SBH from all around the world! The contest's winners were announced live during the main event on October 25th 2022.

Congratulations to Francisca Rojo Cano (24) from Chile who won the first prize of the contest, Emerson Balboa Guajardo (17) from Chile who won the second prize and S. Abinav (9) from India who won the third prize.

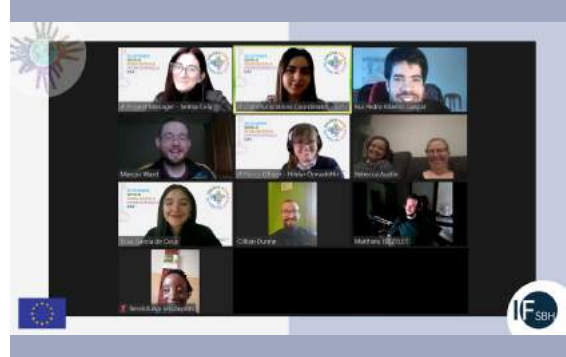
Subsequently, these drawings have inspired three phone wallpapers which were and will be gifted to donors by the IF to thank them for their support.

ESCAPE ROOM

The IF international youth group held the “Digital Escape Room - Unlock Your Right to Health” side-event on October 29th.

This escape room game by the youth for the youth, with Elisa Garcia de Ceca (Member of the IF international youth group) as the ‘master of ceremony’ was a popular and interactive way to learn or strengthen knowledge about the UNCRPD. For this game participants were split into two groups. Each group followed the story of Anna, a fictional SBH advocate who has found herself alone in Geneva for the Conference of State Parties to the UN Convention on the Rights of Persons with Disabilities. The participants competed to solve a series of puzzles which revealed clues to compose a statement for Anna to present at the conference. The main objective of this event was to have fun and learn about the UNCRPD in a relaxed and joyful way.

The youth community expressed their interest in having occasions where they could gather, have fun and exchange ideas among them and really wish to proceed with these activities in the future.



UNLOCK YOUR DIGITAL COMMUNICATION

"From Traditional to Digital - Unlock Your Digital Communication" was another side-event to the WSBHD21 taking place on October 19 2021. This was the first event organised by IF exclusively for Member Associations' Communications persons!

The focus point of this side-event was to highlight the importance of communications, in particular digital communication, in advocating for the rights of individuals with SBH. The panel of speakers together with participants from all around the world shared their experiences, best practices, and strategies in digital communication to unlock individuals with SBH's rights to health by sharing best practices and lessons learned after almost completely switching and relying upon a digital setting due to the pandemic.

The first speaker, Sinem Sari (IF Communications Coordinator) highlighted the importance of a strong network, cross-promotion and learning opportunities from one another during her presentation. She presented the many benefits of social media, especially in advocacy, increasing visibility and building a community.

The second speaker, Daniela Cleto Herrera, Communications officer at Fundación Mónica Uribe Por Amor - FMUPA delivered an overview of inspiring and successful campaigns organised by FMUPA such as the campaign about folic acid "Una vitamina para la vida" ("A vitamin for life") and the "Corre Por Amor" ("Run for love", the word love here is a reference to the name of the organisation as well). Moreover, she shared strategic tips about the use of social media and how to grow your network through reaching more people, generating interactions and gaining new followers.

The third speaker Jack Buckley (Communications Officer at Spina Bifida and Hydrocephalus Ireland - SBHI) focused on strategic communication, especially on emotional marketing and communication. He also covered opportunities social media offers and shared various marketing and communications tools with the participants. Jack also went through the challenges the COVID-19 pandemic brought to SBHI and how they could overcome them. One of the main aspects he covered was the importance of having an up-to-date website, especially in time of a pandemic when this becomes the shop window of the organisation.

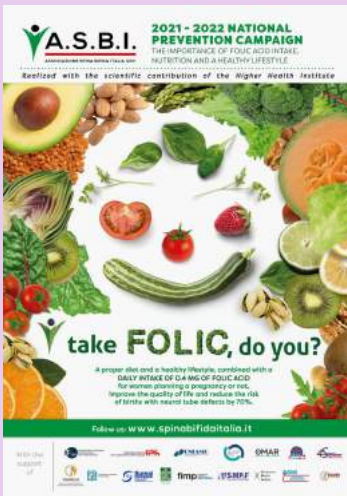
The final speech was presented by Tengku Ari (Communications Officer at Spina Bifida Association Malaysia - SIBIAM). The presentation covered all aspects related to the switch from a traditional to a digital setting, including online events and gatherings with members such as educational trainings. Tengku Ari also emphasised the continuous needs for improvements as the digital world is an ever-changing world. As a conclusion, he stressed the importance of digital media and staying connected to members in any circumstances.

This event was a truly inspiring moment of solidarity between IF members through sharing and learning from one another. Following the success of this communications meeting, IF will add this activity to its yearly calendar.



WSBHD21 SIDE EVENTS

BY IF MEMBERS



ASBI Launched a National Prevention Campaign 2021-2022 in Italia on October 25 2021 in collaboration with the Higher Health Institute

"I take folic, do you? The importance of folic acid, nutrition and a healthy lifestyle", this campaign aims at raising awareness on the importance of food, knowledge of raw materials and their use. On October 25, ASBI presented the first activity of the Campaign, the illustrated calendar 2022, that aims to give tips and be informative about the richest fruits and vegetables in folate.



FFF - SBHAN Held a Multidisciplinary National Discussion on SBH in Nigeria

On October 27th, Festus Fajemilo Foundation (FFF) and Spina Bifida Hydrocephalus Association in Nigeria (SBHAN) jointly organised a multidisciplinary "National Discussion on Spina Bifida and Hydrocephalus in Nigeria" to commemorate the World Spina Bifida and Hydrocephalus Day (WSBHD).



(EN) Let's talk about Rights to Health - (SP) Hablemos sobre los derechos de la salud

On Friday 15 October, Fundación Mónica Uribe Por Amor (Colombia) held a talk on the right to health in collaboration with Carlos Jaramillo, lawyer of the Disability Unit of the city of Medellín - Antioquia. This meeting was held at 4:00 in the afternoon virtually through the Zoom platform. The lawyer gave recommendations to members according to their situations.



SIBIAM's Talent Event

On Friday 30th of October, IF Member Association in Malaysia, SIBIAM, an online event where members could present their talents such as drawing skills, singing and dancing with some prizes as rewards!



ASBAH-SA Organised Multiple Activities in South Africa on the occasion of the WSBHD21

ASBAH-SA started celebrations on October 6 by distributing party packets at the Spina Bifida Clinics every Wednesdays during the month. On October 11, the SBH Clinic distributed gift bags to patients and staff as rewards. Last but not least, a tea time was organised on October 23th with mothers of children with SBH during which Zubeida Toefy and Rozanne Bihl delivered a speech about SBH awareness at the SBH Clinic.



SBF India Gave a Special Musical Concert

IF Member Association in India, Spina Bifida Foundation, held a special music concert on 31st October 2021 on the occasion of the World Spina Bifida and Hydrocephalus Day 2021.



ASBH Video Compilation

To celebrate this special day, IF Member ASBH (France) shared the 2021 edition of the video clip they traditionally prepare with contributions from their members each year on October 25th.

HEALTHY AGEING

On October 27th, the IF working group on ageing with SBH held the “Ageing Well with Spina Bifida and Hydrocephalus” side event to the WSBHD21.

This side event was a follow-up of several activities the IF working group on ageing with SBH organises to bring people together and advocate for the important topic of ageing. Indeed, little is known about ageing with SBH; thus, having discussions among adults with SBH and sharing personal and intimate experiences help others to feel understood.



Chaired by Kevin O'Donnell, the IF working group on ageing with SBH Chairman, this side event was an occasion for adults with SBH to speak up about their experiences and to share their personal testimonies without fear of censure. As an example of what was discussed at this meeting, Mario Sel (member of the Flemish Association for Spina Bifida and Hydrocephalus (VSH)), explained the multidisciplinary care system in Belgium and how at first they were focused on children, but transited later on to adult care due to high demand. He expressed his positive experience of being taken care of by a multidisciplinary team: “We don't lose time to make multiple appointments for different doctors”.

Another topic covered during this side event was mental health. Kevin O'Donnell underscored the link between mental and physical health stating that depression and anxiety are critical for many adults with SBH. However, some demonstrate more resilience in the face of changes in their physical health throughout the years. Kevin shared the importance of twinning with these persons to develop their own resilience. The summary article of this event is available [here](#).



“Ageing Well with Spina Bifida and Hydrocephalus”



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.

IF IS A MEMBER OF:

- 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)



IF HAS AN ONGOING COLLABORATION WITH:

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

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

- APEBI, Argentina
- AVSI Gulu Uganda
- Bethany Kids, Kenya (BK)
- Central Uganda Spina Bifida and Hydrocephalus Network, Uganda (CU-SBH)
- CURE Children's Hospital Uganda (CCHU)
- CURE Zambia
- Festus Fajemilo Foundation, Nigeria (FFF)
- Katalemwa Cheshire Homes Uganda (KCH)
- 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)
- Zambian Association for Hydrocephalus and Spina Bifida (ZAHSB)

IF COLLABORATES ON PROJECTS WITH:

- Bühler
- CDC's National Center on Birth Defects and Developmental Disabilities
- CURE International and CURE Hydrocephalus and Spina Bifida
- Emory University
- European Disability Forum (EDF)
- European Network for Independent Living (ENIL)
- European Parliament
- Food Fortification Initiative (FFI)
- Helen Keller International (HKI)
- Mühlenchemie
- Nouryon
- Nutrition International (NI)
- UNICEF
- World Food Program (WFP)
- Southern African Development Community



COMMUNICATIONS

LETTER COMMUNICATIONS COORDINATOR

The COVID-19 pandemic brought us to adapt and renew our use of social media to maintain a close relationship with worldwide members and partners not only through IF internal and external newsletters, social media channels such as Twitter, LinkedIn, Facebook, Instagram, and WhatsApp, but also through face-to-face online meetings and webinars. This year was pivotal for IF communications with the challenge of staying connected with our members and partners through the implementation of a digital communications strategy, especially since digital communication took over other forms of communications during the pandemic.

We have succeeded in staying connected with one another, in strengthening our relationship and widening our network in 2021!

The solidarity and active participation in advocacy and raising awareness campaigns such as during the World Folic Acid Awareness Week, the International Women's Day, and the World Spina Bifida and Hydrocephalus Day were examples of being connected. Also, the IF meeting with communications coordinators of IF member associations was a good example of strengthening relationships and staying connected.

On national levels, our members conducted wonderful and inspiring campaigns such as Fundación Mónica Uribe Por Amor's (Colombia) "Corre Por Amor" running campaign, Spina Bifida Foundation India's special musical concert on the occasion of the World Spina Bifida and Hydrocephalus Day 2021 as well as their "Fetal Surgery: State of the Art" webinar, SiBIAM (Malaysia) launched their Global Grant: Training Healthcare Professionals and Special Needs Teachers on the Management of Spina Bifida, ASBI Italy launched a Patient Registry for SBH in Italy in June 2021 and a National Prevention Campaign 2021-2022 in Italy on October 25 2021 in collaboration with the Higher Health Institute, ASBH in France held a Press Conference: "Spina Bifida : Face à un fardeau sanitaire lourd, la prévention reste encore timide !" (EN: "Spina Bifida: Against a still too heavy health burden, prevention yet remains timid"), SHA-U (Uganda) released a spina bifida anthem on the World Spina Bifida and Hydrocephalus Day 2021, Festus Fajemilo Foundation (FFF) and Spina Bifida Hydrocephalus Association in Nigeria (SBHAN) showed true solidarity by jointly organising a multidisciplinary "National Discussion on Spina Bifida and Hydrocephalus in Nigeria" to commemorate the World Spina Bifida and Hydrocephalus Day or the launch of a South Asian Network, and countless actions from our worldwide members!

Moreover, IF member associations were visible in the countries they represent and through above mentioned activities within the IF advisory and working groups.

In brief, we found many ways to interact and support each other throughout the year for the unique and common mission of promoting and protecting the rights of persons with SBH.

Online and offline joint actions in 2021 were crucial for the dialogue at national and international levels and to influence policy making processes.

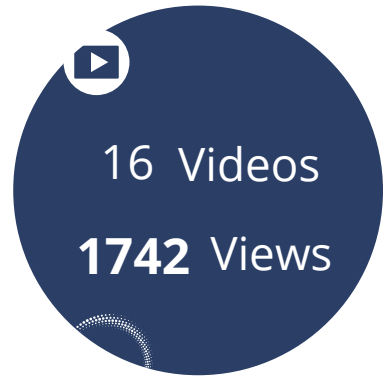
Sinem Sari, IF Communications Coordinator



COMMUNICATIONS AT A GLANCE

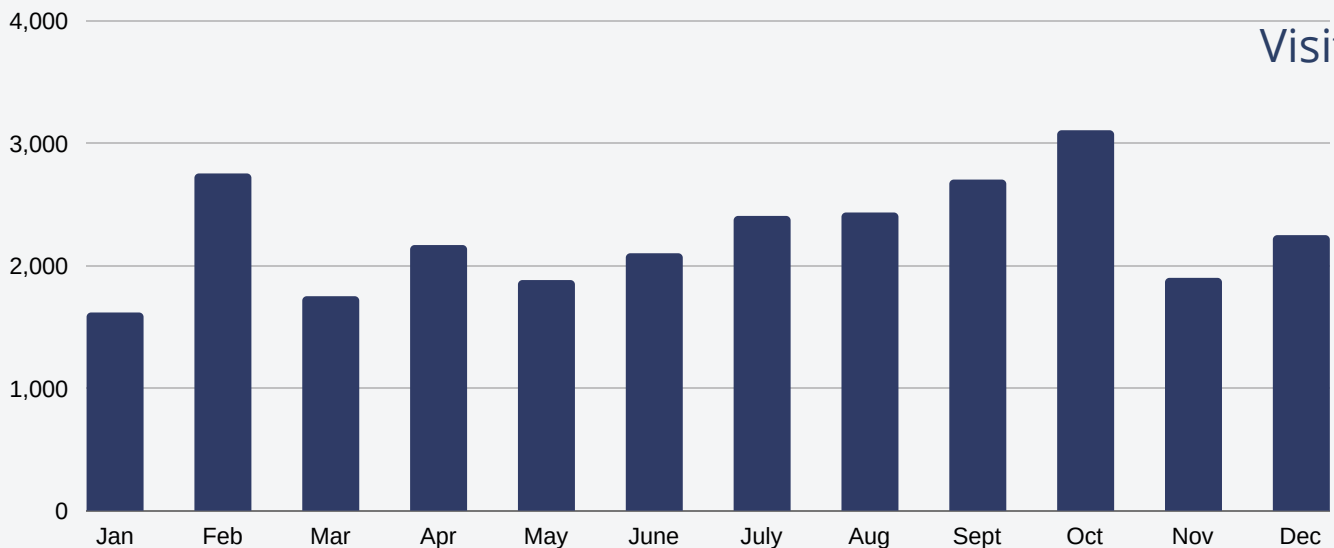
2021 SNAPSHOT

COMMUNICATIONS ACTIVITIES - DATA



Visitors on www.ifglobal.org

26.997
Visitors





FINANCIAL REPORT

AUDITOR'S REPORT TO THE BOARD OF DIRECTORS OF THE INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS ON THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2021

We report to you in our capacity of the organization's auditor. This report includes our opinion on the financial statements. The financial statements include the balance sheet as of 31 December 2021 and the income statement for the year then ended.

Responsibility of the general governance board for the preparation of the financial statements

We have audited the financial statements of the INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS for the year ended 31 December 2021, in accordance with the financial reporting framework applicable in Belgium, which show a balance sheet total of € 510.977 (units) and a profit for the year of € 150.181 (units).

Report on the financial statements - Unqualified opinion

The procedures selected depend on the auditor's judgment, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error.

We have obtained from the general governance board and organization officials the explanations and information necessary for our audit.

An audit also includes evaluating the appropriateness of valuation rules used and the reasonableness of accounting estimates made by the general governance board, as well as evaluating the overall presentation of the financial statements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our qualified opinion.

In our opinion, the financial statements of the INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS give a true and fair view of the organization's equity and financial position as per 31 December 2021 and of the results of its operations for the year then ended, in accordance with the financial reporting framework applicable in Belgium.

Report on other legal and regulatory requirements

In accordance with the applied standard which is complementary to the International Standards on Auditing (ISA's), our responsibility is to verify, in all material respects, compliance with certain legal and regulatory requirements. On this basis, we make the following additional statements, which do not modify the scope of our opinion on the financial statements:

- without prejudice to certain formal aspects of minor importance, the accounting records are maintained in accordance with the legal and regulatory requirements in compliance with the by-laws of the INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS;
- no transactions have been undertaken or decisions taken in violation of the statutes or the Code of Companies and Associations, are done or taken.

Zandhoven, March 15th 2022

Vincent Koopman Chartered Public Accountant

BALANCE SHEET

Assets (€)	31-Dec-2021	31-Dec-2020
TANGIBLE ASSETS	3,913.19	650.79
IT & office supplies	5,637.28	10,794.39
Depreciations IT & office supplies	-1,879.09	-10,794.39
Office furniture	0.00	3,577.83
Depreciations office furniture	0.00	-3,577.83
Cautions	155.00	650.79
AMOUNTS RECEIVABLE	96,211.63	14,356.83
Debtors	58,183.29	14,356.83
Subsidies to receive	38,028.34	0.00
BANK & CASH ACCOUNTS	406,521.16	868,794.43
KBC - accounts	157,133.06	37,406.33
KBC - accounts saving	249,388.10	831,388.10
TRANSIT ACCOUNTS	4,331.07	321.39
Deferred charges	4,331.07	321.39
TOTAL ASSETS	510,977.05	884,123.44

BALANCE SHEET

Liabilities (€)	31-Dec-2021	31-Dec-2020
RESERVES	346,596.36	196,415.06
Funds of IF	196,415.06	199,417.88
Profit-loss bookyear	150,181.30	-3,002.82
PROVISIONS	0.00	3,088.91
Provision relocation	0.00	3,088.91
AMOUNTS PAYABLE	79,619.05	67,258.24
Suppliers	58,143.02	29,725.75
Taxes payable	10,380.98	0.00
Social charges payable	1,287.79	0.00
Provision holiday fee	9,807.26	6,785.39
Divers payable (rent)	0.00	14,040.00
Child Help current account	0.00	23.81
Subsidies EU to return	0.00	16,683.29
TRANSIT ACCOUNTS	84,761.64	617,361.23
Accrued charges	0.00	17,619.97
Deferred income (FFI)	84,761.64	599,741.26
TOTAL LIABILITIES	510,977.05	884,123.44



PROFIT AND LOSS

INCOME (€)	772,400.72
MEMBERSHIP FEES AND DONATIONS	510,186.54
Membership fees	10,152.18
Donations	4,756.63
Other Grants	495,277.73
SUBSIDIES EU	241,632.99
Subsidies EU-progress	241,632.99
GENERAL INCOME	2,186.43
Divers recuperation	2,186.43
FINANCIAL INCOME	768.15
Payment differences	0.08
Exchange differences	768.07
EXCEPTIONAL INCOME	17,626.61
Exceptional profits	17,626.61



PROFIT AND LOSS

ALL COSTS (€)	622,219.42
OFFICE AND OTHER COSTS	117,287.59
Rent office	10,078.50
Office cleaning	703.53
Energy	1,500.00
Office supplies	326.57
Hardware, equipment & furniture	5,806.80
Software, ICT & telephony	2,110.51
Printing	719.85
Website, social media & online marketing	4,225.63
Marketing (strategy), press & publications	6,443.01
Postal costs	398.25
Insurance organisaton & liability	597.17
Other costs GAIN projects	84,377.77
GENERAL COSTS	34,473.25
Translation	1,490.72
Bookkeeping & accountancy	5,806.18
Annual audit	1,936.00
Law firm / legal advice	1,876.83
Social & medical Secretariat	7,409.71
Fee Sodexo	1,016.81
Consultant fees	8,000.00
Travel & accommodation	6,528.81
Representation & external meetings	408.19
SALARY	464,665.50
DEPRECIATIONS AND PROVISIONS	-1,209.82
FINANCIALS AND EXCEPTIONAL COSTS	7,002.90

CONTACT DETAILS

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