2020
ANNUAL REPORT

IFSBH

INTERNATIONAL FEDERATION
FOR SPINA BIFIDA
AND HYDROCEPHALUS

2020

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FOREWORDS

Mrs Elena Monzón de Záppoli
IF President

Dear Friends,

2020 was a difficult and challenging year. While there were lots of discussions about the challenges of COVID-19 for our economy, there is little talk about how the current crisis is impacting the non-profit sectors. COVID has had a damaging impact on the sector. Over the last year, corporate social responsibility has declined across the industry forcing many nonprofits organisations to close their doors. The situation is paradoxical as the need is growing while support is declining. In 2020, our Federation focused on so many needs as well as maintaining its global focus on listening to people around the world. Especially at this time, the world needs unity, humanity, and compassion for those around us.

It was an excellent experience for me to have worked beside different presidents, as it happened to me with Pierre Mertens, Margo Whiteford and Lieven Bauwens. They have given the best for everybody. Thank you, dear presidents, as each of you have given voice to many persons with Spina Bifida and Hydrocephalus (SBH), families, health professionals, politicians, etc. Of course, I must mention our first president, Björn Rundström, who had an excellent vision of founding the federation.

I also wish to mention the work of our staff, our Secretary General, dr Sylvia Roozen, and the whole Board of Directors who dedicate many hours of work to our Federation.

I really thank everybody for the outstanding commitment in the world of SBH. I invite all the members to be together at our General Meeting.

Elena Monzón de Záppoli - IF President

IF is fortunate to work with passionate and dedicated members and partners around the world. In times of a pandemic there is an urgent need to maintain strong advocacy for human rights, primary prevention, as well as optimising management and care for individuals with SBH and their families.

The COVID-19 pandemic changed our work. Activities, collaborations and communications had to be changed from many in-person gatherings to a virtual context. This has led to several adaptations to work in digital settings, improvement of communication work, and exploring cost-effective and impactful ways to make digital IF activities accessible. The IF Board of Directors and the Members Associations together with the IF Secretariat did a tremendous job working together as a team to seek for creative solutions and opportunities to implement the work in digital formats.

These lessons from the past year also define IF's work for the near future. One unique opportunity is the online exchange of experiences and opportunities for collaboration during IF Member's Meetings with presidents of Member Associations in the African, American, Australasian, and European regions. Members indicated that these meetings have been a source of inspiration to strengthen each other's work. Therefore, IF will continue to facilitate these online meetings as well as any action that may arise from them.

Continuation of the development of IF's partnerships with relevant stakeholders is of great importance to further contribute to the level of knowledge and understanding of Spina Bifida and Hydrocephalus. A key activity and core value remains to strengthen the voices of individuals with Spina Bifida and/or Hydrocephalus worldwide.

IF is extremely grateful for the continued support of members and partners. To make 2021 a success IF looks forward to unlocking potentials together with YOU!

"It takes a village to raise a child" – African Proverb

Dr Sylvia Roozen - IF Secretary General

Dr Sylvia Roozen
IF Secretary General

ABOUT IF

WHO WE ARE

The International Federation for Spina Bifida and Hydrocephalus (IF) is the international organisation representing people with Spina Bifida and Hydrocephalus (SBH) and their families worldwide. The organisation founded in 1979, represents Member Associations in countries all over the world with unique and expert knowledge on SBH.

MISSION & VISION

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

The **vision** of IF is a society that guarantees the 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 for 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:
we take the views of children and adults with SBH and their families into account and rely on them in our work. We respect the regional, cultural and socio-economic specificities of our members around the world, and promote a tailored approach to working on SBH issues.

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

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

MEMBERS

Argentina - Asociación Para la 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
Mexico - Asociación Mexicana de Espina Bifida
Peru - Asociación de Espina Bífida e Hidrocefalia del Perú (ASESBIH PERÚ)
USA - Hydrocephalus Association
USA - Spina Bifida Association of America (SBAA)

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)
Croatia - Udruga osoba i roditelja djece sa spinom bifidom "Aurora"
Denmark - Rygmarvsbroksforeningen af 1988
Estonia - MTÜ 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 of (MEOSZ)

Ireland - Spina Bifida Hydrocephalus Ireland (SBHI)
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.)
Norway - Ryggmargsbrokk- og Hydrocephalusforeningen
Poland - Fundacja Spina
Portugal - Associação Spina Bifida e Hidrocefalia de Portugal (ASBHP)
Romania - Asociatia Romana de Spina Bifida si Hidrocefalie
Russia - Association of Spina Bifida & Hydrocephalus St. Petersburg
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 Bífida i Hidrocefàlia (ACAEBH)
Spain - Asociación Madrileña de Espina Bífida e Hidrocefalia (AMEB)
Spain - (AMUPHEB) Asociación Murciana de Padres e Hijos con Espina Bífida
Spain - Federación Española de Asociaciones de Espina Bífida e Hidrocefalia (FEBHI)
Sweden - Spin-Off
Sweden - Rörelsehindrade Barn & Ungdomar (RBU)
Switzerland - Schweizerische Vereinigung zugunsten von Personen mit Spina Bifida und Hydrocephalus (SBH)
The Netherlands - Spina Bifida en Hydrocephalus Nederland
Turkey - Türkiye Spina Bifida Derneği
UK - Spina bifida • Hydrocephalus • Information • Networking • Equality (SHINE)
Ukraine - Parents Association for Spina Bifida and Hydrocephalus 'Lights of Spirit'

Australia - Spina Bifida Hydrocephalus Queensland (SBH QLD)
China - China Association of Persons with Physical Disabilities
India - Spina Bifida Foundation India
Japan - Japan Council for Spina Bifida and Hydrocephalus
Japan - Spina Bifida Association of Japan
Kazakhstan - Spina Bifida Public Association Organisation from Kazakhstan
Malaysia - Spina Bifida Association Malaysia (SIBIAM)
Mongolia - Mongolian Spina Bifida Foundation "Maral Angel"
South Korea - Korea Spina Bifida Patient Association (KSBPA)
Taiwan - Taiwan Spina Bifida Support Society Taiwan Spinal Bifida Association

Algeria - L'Association des Parents et Malades Spina Bifida Béjaïa (APMSBB)
Egypt - Waad Spina Bifida Foundation
Kenya - Spina Bifida and Hydrocephalus Association Kenya (SHAK)
Malawi - Parents Association of Spina Bifida and Hydrocephalus Limited (PASBHL)
Morocco - Association Spina Bifida et Handicaps Associés au Maroc
Nigeria - Festus Fajemilo Foundation
Nigeria - Liron Hydrocephalus Foundation
South Africa - Association for Spina Bifida and Hydrocephalus South Africa
Sudan - Spina Bifida Federal Association of Sudan
Tanzania - Association for Spina Bifida and Hydrocephalus Tanzania (ASBAHT)
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)

BOARD OF DIRECTORS

Mr Lieven Bauwens
IF President
(until June 2020)
Belgium

Mrs Elena Zappoli
IF President
(from June 2020)
Argentina

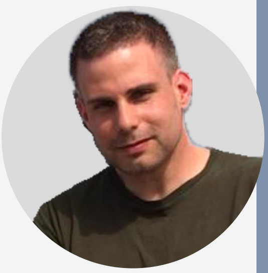
Mr Cato Lie
Treasurer
Norway

Dr Papatya Alkan Genca
Secretary
Turkey

Mrs Emma Suardiaz
Spain

Mrs Giulia Bizzotto
Italy

Dr Aziza Mustafa Elnaeema
Sudan



Mr Rasmus Isaksson
Sweden

Dr František Horn
Slovakia

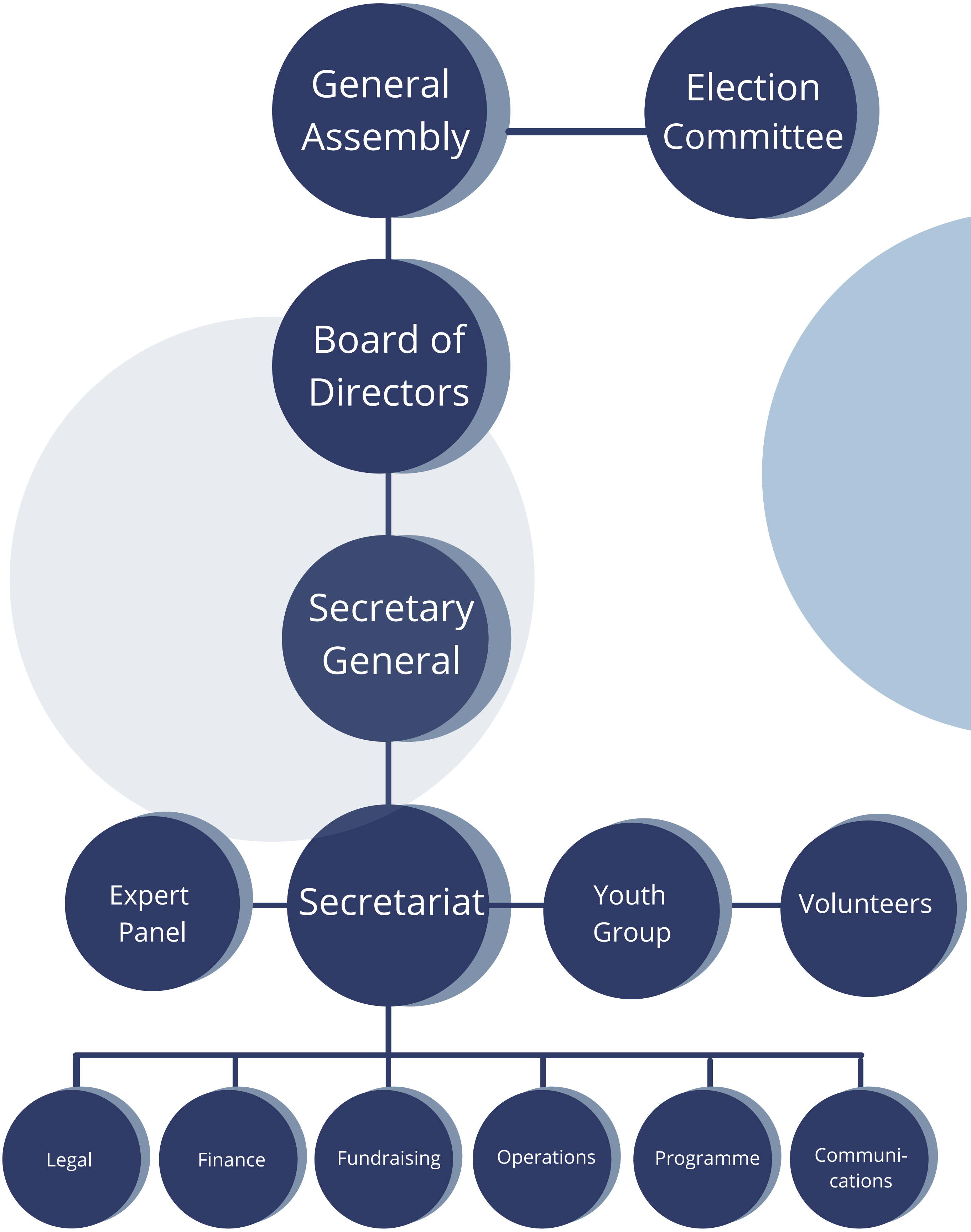
As long-standing member of the IF Team and IF President since 2019, we said goodbye to the outgoing board member Lieven Bauwens during the IF General Meeting, June 2020. The vice president Elena Monzón de Záppoli became the acting president until the upcoming elections of Board Directors.

Secretary General

Dr Sylvia Roozen

IFESH

IF ORGANOGRAM



General Assembly

Election Committee

Board of Directors

Secretary General

Expert Panel

Secretariat

Youth Group

Volunteers

Legal

Finance

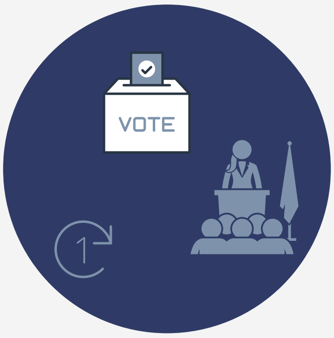
Fundraising

Operations

Programme

Communications

ELECTION COMMITTEE



In 2021, new elections take place for Members of the IF Board of Directors. For this, an Election Committee was established with the following Members:

- Mrs Elena Monzón de Záppoli - Asociación para Espina Bifida e Hidrocefalia (APEBI)
- Dr Margo Whiteford - Spina Bifida Hydrocephalus Scotland (SBHS)
- Mr Tom Scott - Spina Bifida and Hydrocephalus Ireland (SBHI)

ADVISORY PANELS

Our standing committees of advisory groups are the Global Expert Panel, Youth Group and Volunteers.

Global Expert Panel

The Global Expert Panel chaired by Dr Margo Whiteford (Consultant Clinical Geneticist Glasgow, Scotland); Dr Benjamin Warf (Professor of Neurosurgery at Harvard Medical School, United States); David Nolan Morrissey (advocate with Spina Bifida and international disability programs consultant, United States); Dr Amy McPherson (Assistant professor Public Health and Rehabilitation Sciences at the University of Toronto, Canada); Dr Richard H. Finnell (Professor of Molecular and Cellular Biology at Baylor College of Medicine, Houston, United States); and Dr Anne Molloy (Emeritus professor of clinical medicine and Fellow of Trinity College Dublin, Ireland).

Youth Group

The Youth Group includes the following members: Marcus Ward (Ireland); Elisa Garcia de Ceca (Spain); Mirela Bukovac (Croatia); Rui Pedro Gaspar (Portugal); Andela Radovanovic (Montenegro); Elide Bruna (Italy); Eleonora Giannetti (Italy); and Alexandre Jerónimo (Portugal).

Volunteers

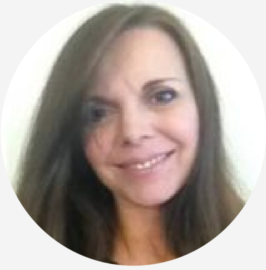
In addition to these advisory groups IF is always fortunate to work with dedicated volunteers. Many thanks to the chairs and to the standing committee members as well as our volunteers.

SECRETARIAT

The secretariat of IF is based in Brussels, Belgium.
The IF Secretariat work would not be possible without the support of the officers serving as linking pins between IF and our Members Associations worldwide. In addition, the help of many individuals and related partner organisations cannot be underestimated for our daily work.

Renée Jopp
Information Officer

Anna Verster
Senior Advisor on Food Fortification



Martine Austin
Programme Manager Global Prevention

Carmen Clemente
Communications Officer (until October 2020)

Verónica Fernández
HR & Administration Manager

Hildur Önnudóttir
Policy Officer

IFSBH

MAIN ACHIEVEMENTS

The calendar below presents a list of the main achievements of 2020. Special attention is given to the important IF topics of right to health, primary prevention, optimising management and care, and international solidarity.

JANUARY

- **Raising Awareness:** IF launched a social media campaign to raise awareness of the World Folic Acid Awareness Week
- **Combining the IDA Programme Committee:** Meetings with our African Member Spina Bifida and Hydrocephalus Association Kenya (SHAK) and our partners Bethany Kids mobile clinic in Naivasha and S.A. Joytown Special Primary School in Thika

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FEBRUARY

- **Advocacy:** IF held a round of introductory meetings with Members of the European Parliament to actively lobby for SBH awareness and rights
- **Raising Awareness:** IF President Lieven Bauwens presented during the 9th International Conference on Birth Defects and Disabilities with a presentation titled: "Eliminating stigma and discrimination against persons with birth defects and disabilities"

MARCH

- **Advocacy:** IF held a meeting with the health attaché of the Permanent Representation of Greece to the European Union to discuss the priorities of the 2020 presidencies of the European Council and to inform the Permanent Representation of Greece of the priorities of IF
- **Raising Awareness:** IF raised awareness during the World Birth Defects Day and International Women’s Day. Furthermore, IF shared resources with Members in response to the global COVID-19 pandemic

APRIL

- **Raising Awareness:** Videos were made by two IF Board Members to provide information with Members on how the pandemic affected their national activities as well as steps they had taken to continue active involvement with their Members

- **Prevention:** IF together with Nutrition International published two Knowledge Briefs on the urgent need for action for NTD prevention, namely: “Preventing neural tube defects in low and middle income countries and the importance of representative organizations” and “The policy environment for folic acid interventions to prevent NTDs”

MAY

- **Raising Awareness:** IF raised awareness for women with SBH and family members of individuals with SBH during the International Day of Families and the International Women’s Month

JUNE

- **Workshop:** IF in collaboration with the IF Working Group on Ageing and speakers from WHO, EUROCAT and the nutrition’s sector organised a series of webinars for members to learn more on the topic of Ageing, Women’s Health, and Prevention

- **Prevention:** IF raised awareness on the topic of self-care including online polls as part of the World Wellbeing Week

JULY

- **Publication:** IF Annual Report 2019

- **Advocacy:** IF had a brainstorming session with MEP Katrin Langensiepen for the report on equality in employment report and an introductory meeting with Emmanuelle Grange DG EMPL

AUGUST

- **Raising Awareness:** active participation during the International Youth Day by the IF Youth Group. The IF Youth Group shared posters with key messages and roleplay videos on important issues such as sexuality, incontinence, and relationship

- **Influencing Policy:** IF launched a Survey on COVID-19 titled: “Impact on people with Spina Bifida and Hydrocephalus (SBH)”

- **Webinar:** IF together with IF Member Association SBF India organised a webinar titled: “A life and the World of Spina Bifida & Hydrocephalus - Reflections and Memories”

SEPTEMBER

- **Prevention:** IF dedicated this month to women's health including social media awareness posts and an online webinar to exchange knowledge and best practices on the important topic of primary prevention

- **Influencing Policy:** IF together with the Validity Foundation, the European Network on Independent Living, Disability Rights International and, the International Disability Alliance responded to The *Lancet* Group Commission on institutionalisation and deinstitutionalisation of children by a correspondence letter

OCTOBER

- **International Solidarity:** IF together with its members and partners celebrated the World Spina Bifida and Hydrocephalus Day (WSBHD) through online social media awareness activities and the first online WSBHD webinar titled "Towards a global spina bifida & hydrocephalus community". Special focus was given to mental health, employment, and human rights

- **Publication:** The IF Working Group on Ageing published the report "Ageing with Spina Bifida and Hydrocephalus - a descriptive analysis"

NOVEMBER

- **Training:** IF organised Human Rights and advocacy training for Youth with SBH. Small interactive online session were held which provided opportunities to enhance skills and understanding of disability rights and advocacy

- **Community Building:** IF in collaboration with IF Member Association ASBI Italy organised a photo competition dedicated on the topic of Human Rights. The top 12 pictures were published in the International SBH Calendar 2021

DECEMBER

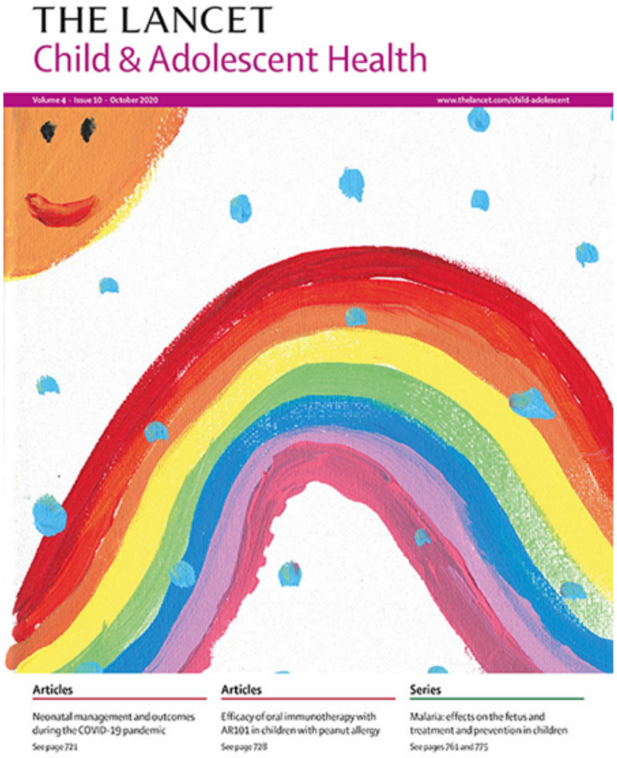
- **Publications:** The IF Working Group on Multidisciplinary Care published the report "Multidisciplinary Care for Individuals with Spina Bifida and Hydrocephalus in Europe - an explorative study 2020". Also, the Task Force SBH & Sexual Health published the report "Insights from Focus Group Discussions on Sexual Health between Individuals with Spina Bifida and Hydrocephalus"

- **Event:** Together with the European Parliament represented by MEP Stelios Kympouroupoulos, the European Disability Forum (EDF), the European Network for Independent Living (ENIL) IF hosted the online event on disability rights and sexual health. Youth with disabilities shared testimonial stories to break the taboo of disability and sex and demanding inclusive sex education and sexual healthcare programmes

RIGHT TO HEALTH

ADVOCACY

The mission of IF is to advocate for the rights of individuals with SBH and their families by calling for the full implementation of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and advocating on topics important to the SBH community including but not limited to access to multidisciplinary care, mental health, ageing with SBH and sexuality. IF achieves this by undertaking a variety of actions, such as connecting with policy makers, seeking feedback from IF Members, publishing and disseminating IF statements, recommendations and reports but also by collaborating with other organisations and actors. In July 2020 IF published a joint letter with the Coalition on the Right to Family Life to the Lancet Group Commission objecting against the claims that institutionalisation of children with disabilities is justified and in accordance with international human rights.



THE LANCET
Child & Adolescent Health

Volume 4 · Issue 10 · October 2020
www.thelancet.com/child-adolescent

Articles
Neonatal management and outcomes during the COVID-19 pandemic
See page 721

Articles
Efficacy of oral immunotherapy with AR101 in children with peanut allergy
See page 728

Series
Malaria: effects on the fetus and treatment and prevention in children
See pages 761 and 775

2020 introduced new challenges to the policy work of IF and the COVID-19 pandemic highlighted the urgency of advancing the rights of persons with disabilities and the SBH community.

COVID-19

IF created an opportunity on the IF website where Members can share useful resources related to the COVID-19 pandemic. Putting the voices of individuals with SBH and their families at the centre of IF's messages on COVID-19 was of paramount importance. Individuals with SBH and their families had the opportunity to share their testimonies of their experiences of the COVID-19 pandemic with IF. These testimonies were collected through Facebook and shared on the IF website. In addition, a survey on Covid-19 was circulated among all IF Member Associations in August 2020. The objective of the survey was to explore the impact of COVID-19 on IF Member Associations as well as the experiences of individuals with SBH and their families. The results of the survey were used to inform IF's policy and advocacy work on the topics of access to healthcare, mental health, and Covid-19.

RIGHT TO HEALTH

The right to the highest attainable standard of health without discrimination on the basis of disability (article 25 of the UNCRPD) was enshrined into IF's policy and advocacy work undertaken in 2020. IF's activities on access to multidisciplinary care, ageing with SBH and sexuality were centred on IF's mission to engage in political advocacy on the issue of health as a human right. In addition to mainstreaming the right to health and access to multidisciplinary care into activities on topics such as services for children, ageing and sexuality. An infographic on article 25 of the UNCRPD was also published for the 2020 World Spina Bifida and Hydrocephalus Day to raise awareness of the right to health.

SEXUALITY

IF continued its important work on the topic of sexuality. In order to bring wider awareness on the topic of SBH, disability and sexuality, IF partnered with the European Disability Forum (EDF), and the European Network for Independent Living (ENIL) to organise an online event hosted by MEP Stelios Kympouropoulos on disability rights and sexual health. Through this partnership further actions are developed to break the taboo of disability and sexual health. As well as steps to advance the rights of individuals with SBH to ensure full implementation of the UNCRPD.

ADVOCACY

Advocacy towards the European Union

The European Union (EU) is an important international actor in disability and health policies with a global relevance. IF continue to advocate to and connect with EU policy makers throughout 2020. Including the health attaché of the Greek permanent representation, as well as numerous members of the European Parliament throughout the year.

IF began the year by publishing a position paper titled "Towards a new European disability strategy for 2020-2030" in January. This document informed IF's continued advocacy towards the European Commission on this important initiative, including the IF's response and participation in public and stakeholder consultations. IF also published its recommendations to the new European Commission 2019 - 2024 as well as a website article on the launch of the European Semester of 2020. In September, IF published a policy paper outlining its concerns and recommendations for the implementation of the new multiannual financial framework of the European Union.

IF contributed to several EU public consultations throughout the year. Including on the European Commission's roadmap on basic services for children in need, the European Commission's roadmap for the strategy on the rights of persons with disabilities, the European Commission's roadmap for the green paper on ageing and the public consultation on gender equality in the EU.

In addition, IF was invited by MEP Katrin Langensiepen to participate in the drafting of the European Parliament report on the implementation of Council Directive 2000/78/EC establishing a general framework for equal treatment in employment and occupation in light of the UNCRPD. Participation in consultations such as these as well as in the High Level Disability Group of the EU and stakeholder consultations organised by the European Commission, is a vital component of IF's work to ensure that the voice of individuals with SBH are heard in policy making.

Monitoring, commenting and participating where possible in these processes raises the profile of IF as a key stakeholder in the field of health and disability policies within and beyond Europe.

LEARNING

The 5th human rights and advocacy training for youth with SBH was held in December of 2020. Due to the COVID-19 pandemic the sessions were held online. Organised over a span of several weeks participants were introduced to key topics on disability rights and advocacy by three fantastic trainers who all have extensive experiences in disability and SBH advocacy. These were Anđela Radovanović from the Association of Youth with Disabilities of Montenegro, Kamil Goungor, from the European Network for Independent Living (ENIL) and the Chair of the European Disability Forum's Youth Committee and Rasmus Isaksson, of the Swedish organisation 'Förbundsordförande DHR' and Board member of IF since October 2019.

The change in format to an online training course required redesigning of the materials and the training. However, it also provided an opportunity to reach participants who otherwise would not have been able to attend, to space out the sessions over a period of weeks and to utilise digital resources for interactive learning.

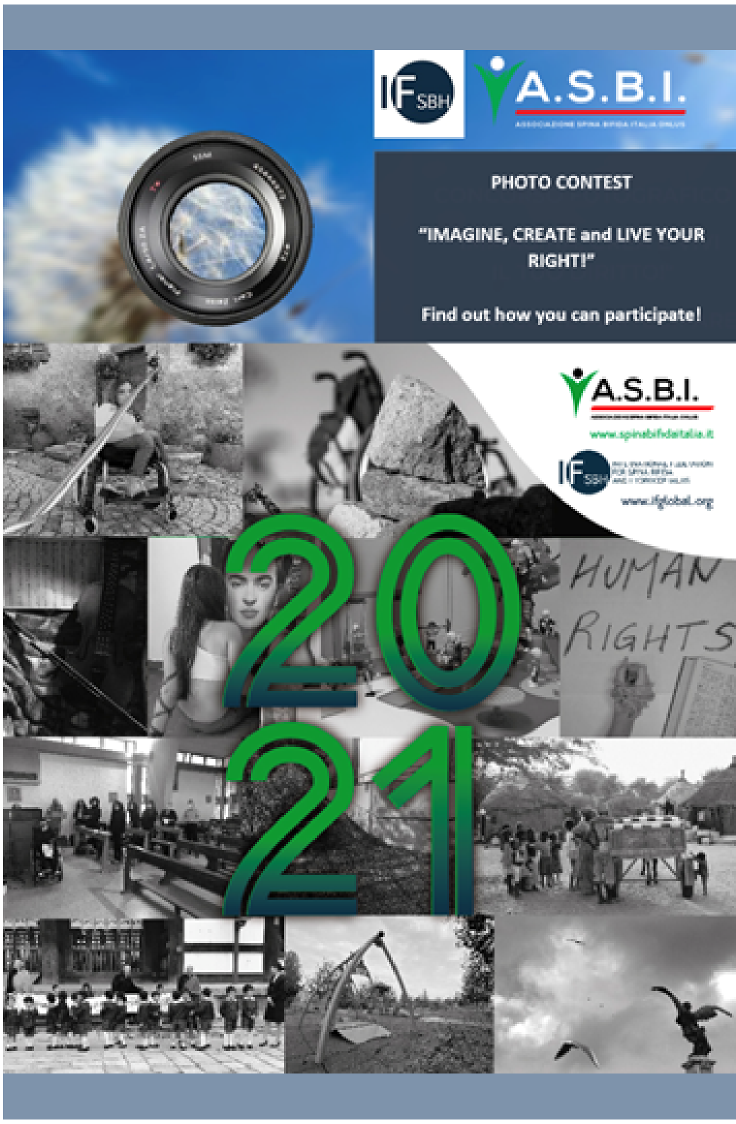
COMMUNITY BUILDING

Using the communicative power of the image to highlight an important and delicate issue such as Human Rights, promoting a moment of creativity and healthy competition, while at the same time stimulating a deep reflection on the need for the implementation of rights in today’s society. With these objectives, IF and the Spina Bifida Italian Association (Associazione Spina Bifida Italia, ASBI) launched the first edition of the photo contest titled “IMAGINE, CREATE and LIVE YOUR RIGHT!”.

The title of the photo competition was inspired by Article 27 of the Universal Declaration of Human Rights where it is stated that: “Everyone has the right to freely participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits”.

In this way, participants were asked to utilise the power of the image as a tool to illustrate the importance of cultural and social participation of people with disabilities within their community.

The competition was of interest to many individuals across Europe. The jury consisted of professional photographers, representatives of the Association and journalists. During the beginning of 2021 the top 12 finalists were chosen. The first three winners received a spot at the upcoming photo exhibition. Also, all 12 finalists were shown in the 2021 International SBH Calendar. IF congratulates these excellent photographers!



PREVENTION

For Neural Tube Defects (NTDs), in particular Spina Bifida, integrated primary prevention, secondary and tertiary prevention (e.g., early diagnosis, optimal management and care) goals are important. Activities contributing to better awareness and optimising quality of life are of great importance. As such, IF together with its Member Associations and partners worldwide have already carried out a wide variety of SBH prevention and management activities such as mobilising advocacy, national awareness campaigns, international solidarity programmes, knowledge acquisition, and tailored training programs. IF's activities in 2020 which sought to actively influence primary prevention as well as optimise management and care are described below.

A Global Event
The Spina Bifida Foundation (India) along with
The International Federation for Spina Bifida & Hydrocephalus presents....
A Life and Global Leadership for Spina Bifida Prevention and Research

Saturday, 3rd October, 2020 | 9.00am (EDT) | 3.00pm (CEST) | 6.30pm (IST)

Dr. Godfrey P. Oakley Jr., MD, MSPM
- Research Professor, Department of Epidemiology, Emory University, Atlanta
- The world's leading voice and global ambassador for folic acid-based prevention of birth defects
- Champion for staple food fortification with folic acid
- Director, Center for Spina Bifida Prevention, Emory University, Atlanta
- Former Director, Division of Birth Defects and Developmental Disabilities Branch, CDC, Atlanta
- Winner of several awards for his life's work on spina bifida prevention, including 2020 Kenneth Rothman Career Achievement Award from the Society for Epidemiologic Research

In conversation with

Dr. Santosh Karmarkar, MD
- Founder Trustee Spina Bifida Foundation (India)
- Pediatric Surgeon & Urologist, Lilavati Hospital, Mumbai
- Former member Board of Directors IFSBH
- Public Health Activist

Dr. Vijaya Kancherla, MS, PhD
- Research Assistant Professor, Department of Epidemiology, Emory University
- Epidemiologist, Center for Spina Bifida Prevention, Emory University
- Former Board Member, Spina Bifida Association of Georgia, US
- Former Pierre Decouflé Post-Doctoral Fellow, National Center on Birth Defects and Developmental Disabilities, CDC, Atlanta

We welcome you to join us online for this special event.

Primary Prevention

In 2017, IF launched the Global Prevention Initiative (IFGPI). The goal of the IFGPI is to unite IF Member Associations, relevant NGOs, Governments, policy makers, health services, health professionals and individuals to maximise the risk reduction of NTDs, in particular Spina Bifida and Hydrocephalus.

The IFGPI supports member states in developing national plans for implementation of effective interventions to prevent birth defects, including the development and delivery of effective prevention initiatives and food fortification strategies, in line with the aims of the World Health Organisation.

As part of the IFGPI initiative, several actions take place throughout the year. Some highlights of activities in 2020 are described below.

World Folic Acid Awareness Week

Each year the International Federation for Spina Bifida and Hydrocephalus works together with its Member Associations, partners and supporters to promote the World Folic Acid Awareness Week as part of the IF Global Prevention Initiative to advocate for the urgent need for prevention efforts of NTDs and Hydrocephalus. With the support of Vitabiotics Pregnacare, IF developed and disseminated a toolkit, including links, hashtags, banners and our logo for download, and suggested messages to share throughout World Folic Acid Awareness Week.

Women's Health Wednesday Campaign

IF continued to share weekly social media polls as part of the IF initiative *Women's Health Wednesday Campaign*. Through polls and posts on several channels IF aims to contribute to levels of awareness and knowledge on healthy pregnancies for all women in reproductive age, as well as their partners, families and IF's wider community. Each poll either addresses a particular topic or corresponds to a relevant topical international awareness day or week, such as the International Day of Action for Women's Health or World Folic Acid Awareness Week. Each post comprises general information on that particular weeks' topic (to increase awareness and knowledge), followed by a corresponding poll question which is aimed at assessing levels of comprehension of the material.

The IF Women's Health Wednesday Campaign furthermore assists to identify and increase understanding of potential gaps in women's (i) knowledge and understanding around important topics connected to their health, lifestyle, sexual and reproductive health and preconception health and pregnancy; and to (ii) communicate important information on relevant women's health topics to improve topic specific knowledge and comprehension.

For this year topics of interest included the pandemic, well-being and self-care. Also, emphasis was given to the topics of maintaining mental and physical health. As part of the Global Prevention Initiative, IF will continue its involvement to contribute to an improved health literacy for mothers-to-be as well as their partners.

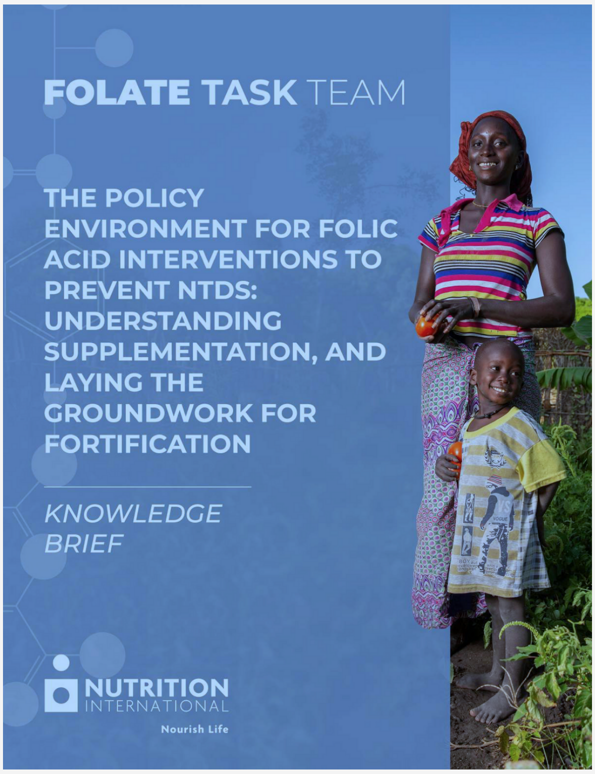
Prevention Clinics

The concept for the Prevention Clinics was driven by IF's mission to reduce the global incidence of these birth defects and as a result of knowledge acquired during the first two years following the implementation of the IFGPI. The Prevention Clinics aim to (i) assess and address clear gaps in data, knowledge and understanding of the problem and its true scope (due to limited coverage of birth defect registries and surveillance); (ii) engage key stakeholders and policy makers; (iii) help address the universal lack of representation and active engagement of those affected in informing prevention policy and strategy, advocacy, awareness raising and the actioning and monitoring prevention activity, by building capacity and empowering those affected by these conditions to become active stakeholders in prevention; (iv) deliver impact at community, national and international levels.

In 2020, Prevention Clinics were held with eight IF Member Associations in Estonia, Ethiopia, India, Italy, Malawi, Nigeria, Turkey, and Uganda.

Prevention Clinics are able to directly help meet this need to empower and mobilise our global network of representative organisations to become active/more active key stakeholders in prevention policy, awareness raising, advocacy, research, community building, education and surveillance, enabling them to have a powerful impact on effectiveness and success of such initiatives. In this respect the project builds on the existing findings of IF's Smarter Futures partnership, PULL strategy. IF published the results of the pilot project (2019-2020) in a report.

To support representative organisations in their advocacy efforts, IF together with Nutrition International published two policy briefs titled "The Policy Environment for Folic Acid Interventions to Prevent NTDs" and "Preventing Neural Tube Defects in Low and Middle Income Countries and the Importance of Representative Organizations".

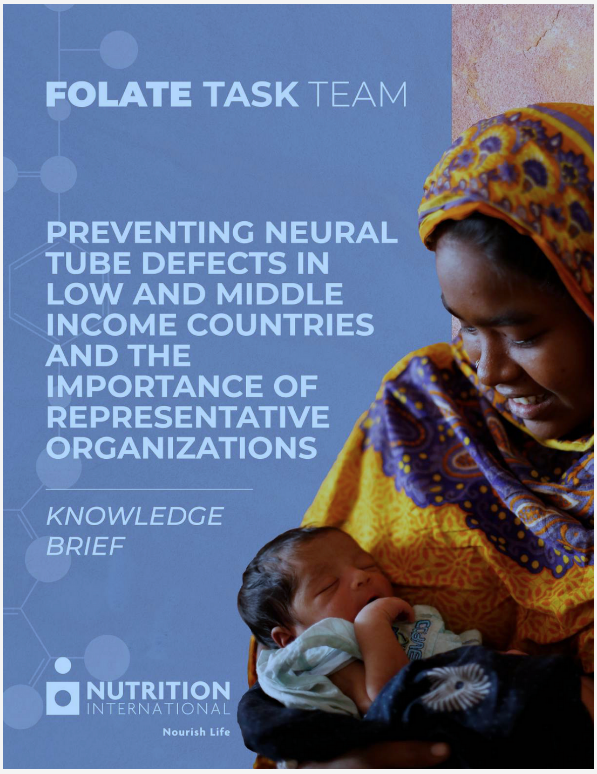


FOLATE TASK TEAM

THE POLICY ENVIRONMENT FOR FOLIC ACID INTERVENTIONS TO PREVENT NTDS: UNDERSTANDING SUPPLEMENTATION, AND LAYING THE GROUNDWORK FOR FORTIFICATION

KNOWLEDGE BRIEF

NUTRITION INTERNATIONAL
Nourish Life



FOLATE TASK TEAM

PREVENTING NEURAL TUBE DEFECTS IN LOW AND MIDDLE INCOME COUNTRIES AND THE IMPORTANCE OF REPRESENTATIVE ORGANIZATIONS

KNOWLEDGE BRIEF

NUTRITION INTERNATIONAL
Nourish Life

Webinar

As part of ongoing prevention activities, this year two webinars were organised to reflect on current actions and explore opportunities to strengthen actions in the near future. The first webinar taking place in June focussed on women's health, NTD prevention and COVID-19. During this webinar four speakers shared their perspectives including: Martine Austin (IF's external consultant on prevention) who spoke about the IFGPI initiative and women's health literacy; Prof. dr Joan Morris (Professor of Medical Statistics and primary investigator EUROlinkCAT study) who mentioned the current data on NTDs in Europe and the important role EUROCAT can play in steps of prevention; Ursula Arens (independent nutrition consultant writer) who mentioned the importance of optimum nutrition for women of childbearing age; and dr Neerja Chowdhary (WHO - Department of Mental Health and Substance Use) who spoke about the important topic of parental mental health and well-being during the COVID-19 pandemic.

The second webinar took place in September which focused on a country perspective with respect to prevention and advocacy. IF Board Member Giulia Bizzotto (Associazione Spina Bifida Italia - ASBI) shared how Italy has set steps towards understanding the scope of the problem of NTDs in Italy.

IF SBH GLOBAL PREVENTION INITIATIVE

IF GPI TALKS

Chapter I with Giulia Bizzotto
IF Board Member, ASBI (Italy)

"Learning from ASBI's experience on primary prevention"

25 September 2020
5pm CET time

Examples of national awareness campaigns were also shared. Italy has taken great steps to systematically register congenital anomalies through a new registry. In the upcoming year the national Italian registry specifically for Spina Bifida will be launched.

Smarter Futures

As of 2020, Smarter Futures partners include the Food Fortification Initiative (FFI) as the main implementing partner, the International Federation of Spina Bifida and Hydrocephalus (IF), Nouryon (formerly AkzoNobel), Helen Keller International (HKI), the World Food Program (WFP), Mühlenchemie, Bühler, Nutrition International (NI), the Global Alliance for Improved Nutrition (GAIN), and the Dutch Ministry of Foreign Affairs.

Smarter Futures (1) does not itself invest large programme resources but supports and strengthens the efforts of its network partners. Current Smarter Futures funding comes from the Dutch Government and from GAIN runs for 2018-2021.

SMARTER FUTURES

A BRIEF OVERVIEW

Smarter Futures is a unique public-private-civic partnership, focused specifically on Africa, that provides technical support to grain millers, governments, vitamin and mineral suppliers, international organizations, and academic institutions to make fortification of wheat flour, maize flour, and rice a reality.

As of 2020, Smarter Futures partners include the Food Fortification Initiative (FFI) as the main implementing partner, the International Federation of Spina Bifida and Hydrocephalus (IF), Nouryon (formerly AkzoNobel), Helen Keller International (HKI), the World Food Program (WFP), Muhlenchemie, Buhler, Nutrition International (NI), the Global Alliance for Improved Nutrition (GAIN), and the Dutch Ministry of Foreign Affairs.

Smarter Futures does not itself invest large programme resources but supports and strengthens the efforts of its network partners. Current Smarter Futures funding from the Dutch Government and from GAIN runs for 2018-2021.

Photo: Rod Waddington

OUR GOALS AND UNIQUE CONTRIBUTION

Smarter Futures has two main goals:

1. Improve the health of all, particularly women of childbearing age, adolescents girls, and children across Africa through the fortification of wheat flour, maize flour, and rice with essential vitamins and minerals, notably iron and folic acid, through the provision of technical support, and
2. Work with partner agencies in similar countries, regions, and across similar domains while simultaneously ensuring complementarity of approaches.

Smarter Futures is unique in that it:

1. Brings together key stakeholders (i.e. government officials, millers, and civil society actors) involved in grain fortification and stimulates exchanges at the regional level, providing opportunities to share experiences and motivate countries to follow the examples and progress achieved by other countries.
2. Places a particular focus on the involvement and inclusion of civil society actors such as disability groups, consumer associations, physicians and neurosurgeons, and parent associations related to spina bifida and hydrocephalus through the involvement and actions of International Federation of Spina Bifida and Hydrocephalus (IF).

As project holder, IF is driven by its mission to decrease the birth prevalence of spina bifida and hydrocephalus through primary prevention, especially fortification of folic acid, to improve the quality of life for those living with these disabilities. IF represents Members Associations in 14 countries 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.

smarterfutures.net

Photo: Julien Harneis

smarterfutures.net

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How does Smarter Futures work?

(i) *Through advocacy* on the importance and cost-benefit of fortification, providing training to parents of children with preventable birth defects, and expanding advocacy through a more active involvement of civil society in advocacy and monitoring. Advocacy is also provided to Ministers of Finance and Economic Affairs on the costs and benefits of flour fortification, to ensure their willingness to invest and reduce taxes on imports of premix and to millers on the importance of their role in reducing birth defects and to help ensure compliance.

(ii) *Through developing and expanding strategies for grain fortification* using the African Maize Fortification Strategy and the Rice Fortification Feasibility study for Africa which were both completed in 2016.

(iii) *Through building capacity* for quality assurance and quality control (QA/QC), fortification technology, and *developing and disseminating suitable tools* for appropriate fortification and for training.

(iv) *Through supporting countries technically in monitoring and surveillance*, using available data sources to see trends in iron deficiency anaemia prevalence, as well as birth surveillance of NTDs. As tool for low-cost surveillance Smarter Futures developed Fortimas, an approach for tracking the population coverage and impact of a flour fortification programme.

(v) *Through providing technical assistance* to address current hurdles in implementation at country level and solve problems related to fortification.

IF is dedicated to continuing its mission to decrease the birth prevalence of spina bifida and hydrocephalus through primary prevention, especially fortification of folic acid, to improve the quality of life for those living with these disabilities. For more information, see https://www.smarterfutures.net.

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(1) Smarter Futures (2020). *Smarter Futures a Brief Overview*. https://www.ifglobal.org/wp-content/uploads/2021/01/Smarter-Futures-brochure.pdf

OPTIMISING MANAGEMENT AND CARE

IF Working Group on Multidisciplinary Care

Spina Bifida and Hydrocephalus is a multifaceted condition requiring a multidisciplinary care approach. 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 conducted an exploratory study on the best practices of multidisciplinary care through example practices from six member associations.

IF SBH INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

Multidisciplinary Care for Individuals with Spina Bifida and Hydrocephalus in Europe

An explorative study

December 2020

The report “Multidisciplinary Care for Individuals with Spina Bifida and Hydrocephalus in Europe - an explorative study 2020”(2) builds upon a scoping literature review conducted in 2018 by IF in collaboration with Ghent University. In 2019 input was obtained from six member associations to provide country examples in relation to multidisciplinary care.

The relevance of multidisciplinary care as an important health aspect for individuals with spina bifida and hydrocephalus and their families was highlighted. As illustrated in this report, for the multidisciplinary care for individuals with spina bifida and hydrocephalus, there is ample room for improvement.

Activities by six national member associations reflect the importance of multidisciplinary care. Members have emphasized on the need for guidelines, holistic approaches, registries, training, and involvement of people with SBH.

With respect to future studies into the multidisciplinary care for individuals with spina bifida and hydrocephalus, it is recommended to also investigate commonly neglected paediatric problems such as mental health, sexual health, and sleep problems.

Besides our current understanding on the important topic of multidisciplinary care, it is also meaningful to take into account possible factors prohibiting effective integrative approaches on national level. Analysing interactions between science, practice, and policy is therefore of utmost importance.

On a European 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.

For example, IF is actively involved within the patient centred network ERN-ITHACA. With this network, the ERN-ITHACA stimulates pan-European capacity building activities for management and care for individuals with spina bifida and hydrocephalus. In this way, patient representatives together with clinicians, and lay organisations aim to develop best practices and initiate guideline development where required.

Decisions about prioritising integrated healthcare approaches to pursue in the near future are important. For individuals with spina bifida and hydrocephalus and their families, multidisciplinary care requires an improved approach, emphasizing on the reality of the complex factors between science, practice, and policy.

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(2) IF Working Group on Multidisciplinary Care (2020). *Multidisciplinary Care for Individuals with Spina Bifida and Hydrocephalus in Europe: An explorative study*. https://www.ifglobal.org/wp-content/uploads/2021/03/Multidisciplinary-Care-for-Individuals-with-Spina-Bifida-and-Hydrocephalus-in-Europe-An-explorative-study-2020.pdf

IF Youth Group

Young people with spina bifida and hydrocephalus can and want to have a sexual life as good as everyone else, we should also be part of your target group when talking about sexual life studies.

#YouthDay

During the International Youth Day, the SBH youth community actively raised awareness using social media. This year the IF Youth Group decided to raise awareness for SBH and the issues facing young people with these conditions when it comes to sexuality. They shared a letter through IF website and created materials to be shared on social media: key messages, posters and two role-play videos!

IF Task Force SBH and Sexual Health

Following the active work in 2018-2019 by the IF Youth Group on sexuality and body awareness among youth with Spina Bifida, this year IF welcomed members to participate in activities on the topic of sexual health.

In November, IF facilitated several focus group discussions on the important topic of sexual health among its members. The focus group discussions were led by trained members of the IF Task Force SBH and Sexual Health who are themselves individuals with SBH. The results and recommendations for the way forward are presented in the report "Insights from Focus Group Discussions on Sexual Health between Individuals with Spina Bifida and Hydrocephalus”. (3)

IF SBH INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

Insights from Focus Group Discussions on Sexual Health between Individuals with Spina Bifida and or Hydrocephalus

by
The IF Task Force SBH & Sexual Health
2020

As illustrated in this report, for the topic of sexual health for individuals with spina bifida and hydrocephalus, there is ample room for improvement. Discussions among the in total 14 participants reflect the importance of sexual health as an important aspect of human right. Participants have emphasized on the need for further initiatives and provided several suggestions on the way forward.

With respect to future studies into the topic of sexual health for individuals with spina bifida and hydrocephalus, it is recommended to also investigate aspects including, but not limited to, common beliefs held by the general public, mental health interpersonal communication, and improvement of management and care.

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(3) IF Task Force SBH and Sexual Health (2020). *Insights from Focus Group Discussions on Sexual Health between Individuals with Spina Bifida and or Hydrocephalus.* https://www.ifglobal.org/wp-content/uploads/2021/03/Report-Sexual-Health-SBH-2020.pdf

Besides our current understanding on the important topic of sexual health, it is also meaningful to take into account possible factors prohibiting effective integrative approaches on (inter)national level. Analysing interactions between science, practice, and policy is therefore of utmost importance.

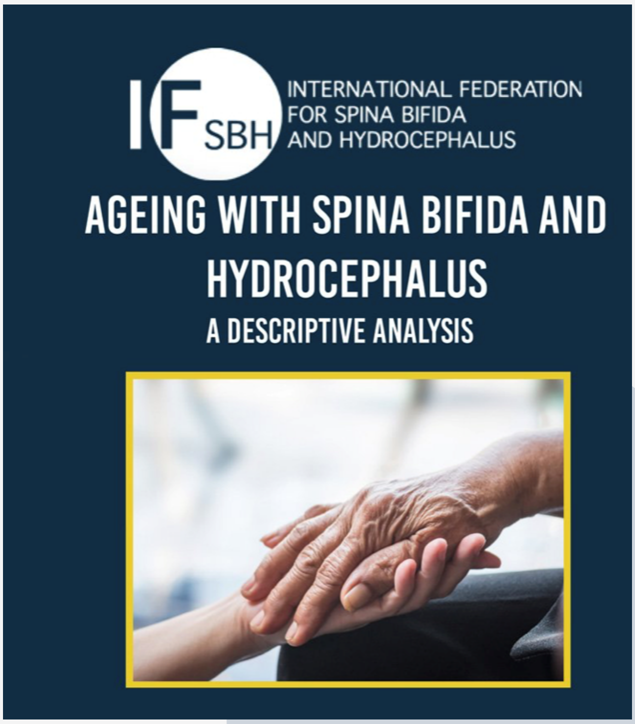
The aforementioned online event hosted by IF together with MEP Stelios Kympouropoulos and in close collaboration with the European Disability Forum (EDF), and the European Network for Independent Living (ENIL)on disability and sexual health was a significant first step for this.

Given the importance of this topic, the clear signals form this report, and recognizable aspects to all IF's members, in the near future further actions will be planned and prioritized.

IF Working Group on Ageing

Healthy ageing is another important topic for IF and its members. The IF Working Group on Ageing has set several steps to improve management and care for those ageing with SBH.

In 2020, the results of a first explorative study were published in IF's report "Ageing with Spina Bifida and Hydrocephalus – a descriptive analysis".(4) It highlights the rights and needs of adults with spina bifida and hydrocephalus and includes a set of recommendations to work towards preventing or minimising the ill effects of ageing and to help improve the quality of life of people ageing with SBH.



IF SBH INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

AGEING WITH SPINA BIFIDA AND HYDROCEPHALUS

A DESCRIPTIVE ANALYSIS

In June, as part of the first ever online IF European Workshop, due to the COVID-19 pandemic, IF organised a webinar on preliminary findings Survey on Ageing with SBH. The workshop provided participants with more detailed information on the first results of the survey conducted in 2019. The results reflected feedback from 650 respondents.

SESSION III

Working Group on Ageing

30 June 2020
2pm-3pm CET

Introduction and moderator

Cato Lie, IF Board member from Ryggmargsbrokk-og hydrocephalusforeningen (Norway)

IF Survey: Ageing with SBH

Sharon Levy, Spina Bifida and Hydrocephalus Scotland

IF Survey: Ageing with SBH

Kevin O'Connell
Researcher

IF SBH INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

Co-funded by the European Union

Last but not least, the European Commission published a roadmap for the Green Paper on Ageing, to which IF responded based on the work done by the IF Working group on Ageing with SBH. For the past years, the evolving demographic changes have been a political priority for European policy makers. And even though those changes are not unique to Europe and that global political actors begin to address the needs of an ageing society, it's imperative that the rights and unique needs of individuals with SBH are taken into consideration.

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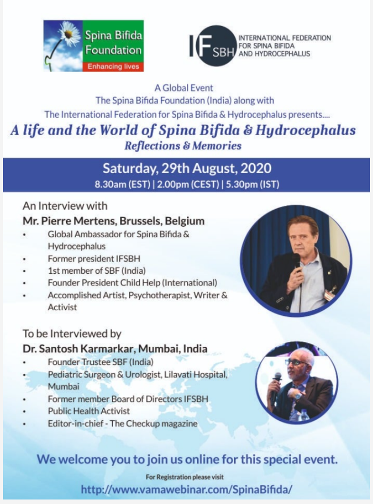
(4) IF Working Group on Ageing (2020). *Ageing with Spina Bifida and Hydrocephalus: A descriptive analysis.* https://www.ifglobal.org/wp-content/uploads/2020/09/IF-report-Ageing-SBH-2020-final.pdf

European Reference Networks

IF has an active role as a patient representative organisation for persons with Spina Bifida and Hydrocephalus within the European Reference Networks (ERN-ITHACA). This patient centred European network aims to meet the needs of persons with rare congenital malformations and syndromes with intellectual and other neurodevelopmental disorders.

In equal partnerships the network brings together patients, their families, and lay organisations to develop best practices and initiate guideline development where required.



Spina Bifida Foundation
Enhancing lives

IFSBH INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

A Global Event
The Spina Bifida Foundation (India) along with
The International Federation for Spina Bifida & Hydrocephalus presents....

A life and the World of Spina Bifida & Hydrocephalus
Reflections & Memories

Saturday, 29th August, 2020
8.30am (EST) | 2.00pm (CEST) | 5.30pm (IST)

An Interview with
Mr. Pierre Mertens, Brussels, Belgium

- Global Ambassador for Spina Bifida & Hydrocephalus
- Former president IFSBH
- 1st member of SBF (India)
- Founder President Child Help (International)
- Accomplished Artist, Psychotherapist, Writer & Activist

To be Interviewed by
Dr. Santosh Karmarkar, Mumbai, India

- Founder Trustee SBF (India)
- Pediatric Surgeon & Urologist, Lilavati Hospital, Mumbai
- Former member Board of Directors IFSBH
- Public Health Activist
- Editor-in-chief - The Checkup magazine

We welcome you to join us online for this special event.

For Registration please visit
http://www.vamawebinar.com/SpinaBifida/

IF is actively involved within the ERN Working Group Spina Bifida to support clinical guideline development covering most of the urological field for paediatrics, transition, and adulthood. The aim of such guidelines is to improve and optimize management and care for individuals with Spina Bifida and their families. For this a panel of experts has been established.

Through multidisciplinary working groups, including IF as a patient representative organisation and clinicians, the guidelines will be further developed in the upcoming year.

INTERNATIONAL SOLIDARITY

The World Spina Bifida and Hydrocephalus Day (WSBHD)

The World Spina Bifida and Hydrocephalus Day (WSBHD) on October 25 was a very special highlight on our International agenda. It gave us the opportunity to raise awareness on SBH and share our stories with our stakeholders. It also enabled us to celebrate achievements, to connect with you in person and to thank you for your part in promoting and protecting the human rights of people with Spina Bifida and Hydrocephalus.

With the great assistance of Dr Santosh Karmarkar and his team from the Spina Bifida Foundation India, IF was able to host this online even. During this first online WSBHD event, a panel consisting of speakers from Member Associations from different parts of the world presented their work and future thoughts on the WSBHD.

The first presentation was given by Dr Santosh Karmarkar of Spina Bifida Foundation India who provided an excellent overview on a global SBH perspective. From his presentation, it becomes clear that if we want to aim for a united world, we need to strive for equal human rights and medical care for both low and high-income countries. The work undertaken by SBF-India shows a good example on collaborations through outreach programs. In this way, counselling and treatment options are made available for those in need. From a global perspective, there is a need to continue activities on primary prevention and work towards global specialised medical care. As mentioned by Dr Karmarkar, there remains to be a need to improve SBH registries, awareness, primary and secondary management of care, as well as global funds to support the work.

The global perspective talk was followed by presentations from different Member Associations (Spina Bifida Association Argentina - APEBI; Spina Bifida Foundation India; Spina Bifida Association Malaysia - SIBIAM; the Norwegian Association Ryggmargsbrokk- og Hydrocephalusforeningen; the charitable foundation Spina Bifida in Russia; Spina Bifida and Hydrocephalus association of Uganda - SHA-U; Spina Bifida Association of America). It was inspiring to learn from the many activities undertaken in the different parts around the world.

The presentation by Ir Dr Kribanandan G N showed a recent journey on how the Spina Bifida Association Malaysia (SIBIAM) works towards strengthening partnerships and raising awareness on SBH. The Association Malaysia furthermore applied for an important grant to work through a nationwide program to translate current knowledge into actions in Malaysia.

On behalf of the Norwegian Association Ryggmargsbrokk- og Hydrocephalusforeningen, Hans Christian Norseth shared a best practice example on how relatively smaller organisations benefit from the collaboration with neighbouring countries. The Norway, Sweden, and Denmark collaboration has shown to be fruitful in strengthening each other's knowledge by sharing information in a cross-border setting.

Sara Struwe on behalf of the Spina Bifida Association of America shared how a multilevel and inclusive approach benefits the Spina Bifida community in the United States. Through research, clinical care, advocacy, education and support, and network building, the Spina Bifida Association of America will continue their efforts to build a better and brighter future for all impacted by Spina Bifida.

A recent journey was shared by Anna Polevskaya from the charitable foundation Spina Bifida in Russia. Through the example of a young boy of eight years old with Spina Bifida, the charitable foundation Spina Bifida in Russia support families with the perspective on abilities instead of disabilities.

From the words shared by Ruth Nalugya by Spina Bifida and Hydrocephalus Association of Uganda (SHA-U), an important message on human rights was shared. Ruth underlined that it is the duty of all stakeholders to protect and promote the human rights for persons with SBH. To ensure that no one is left behind, SHA-U holds dialogue meetings with both the community and ministries.

During the presentation by Elena Monzón de Záppoli (IF President) on behalf of the Spina Bifida Association APEBI in Argentina, an overview was presented on community-based approaches by Latin-American Members, including Carolina Chávez from Bolivia, Patricia Rodriguez from Ecuador, Scarleth Real and Dr Juan Bosco from Nicaragua, Luciano Moreta from Dominican Republic, Federico Nuñez Perea and Stephanie Nuñez Iturrieta from Mexico, Guatemala, Colombia, Paraguay, Costa Rica, Panama, and Chile.

Last but certainly not least, the presentations were followed by other excellent speakers: Rajpal Salgado (Sri Lanka), Olefunke Ogunrombi (Nigeria) and Victoria Sandoval (Guatemala). The speakers presented their inspirational stories on how it is to live with SBH and underscored the need to work together to make SBH prevention a reality.

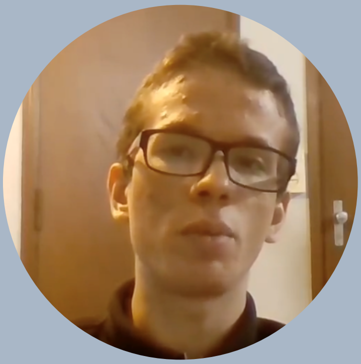
The World Spina Bifida and Hydrocephalus Day (WSBHD) is an important annual event where communities around the world raise awareness for individuals with SBH. IF Members around the world shared their testimonial videos and pictures of their activities for others to follow. As stated by, for example, Belén Hernandez from Guatemala, there is a dream to be united and perceive persons with SBH not as different: "*I dream of a world where disability is normalized and not seen as something strange*".

This year's WSBHD highlighted several topics to be important, especially primary prevention and improvement of management and care for both individuals with SBH and their families. IF trusts this meeting inspired the work you are doing for your communities. As Dr Santosh Karmarkar put it nicely, "*We hope this meeting will sow the seeds for a stronger alliance for our common cause*".

IF thanks all speakers for their inspiring talks in this format. Please find below some inspirational messages from Members around the world.

"I dream of a world where disability is normalised and not seen as something strange."

- Belén Hernandez, from Guatemala.



"Barriers are not the same size for everybody. Sometimes achieving something requires more effort from someone but I am sure that there are no obstacles that are overwhelming in front of a willpower and a desire to live."

- Abel Ferreira, member of IF Member Association APAEBHI in Paraguay.

"Learning how to catheterize myself gave me confidence. Being able to manage myself allowed me to live on and move on. With this confidence, I have a good outcome from life and I do not allow all the challenges to put me down!"

- Olufunke Omodele Ogunrombi, member of IF Member Association Festus Fajemilo Foundation, from Nigeria.

"It's important that we are defined by our goals and what we want to achieve in life and we don't have to let SBH define our lives. Clearly, it's a struggle but every single person in the World has to struggle to deal with. And, if we see our lives from a positive point of view, we are going to profit very much of our lives and see the opportunities presented to us every single day."

- Victoria Sandoval, member of IF Member Asociación Guatemalteca de Espina Bífidia, Guatemala.

IFSBH

NETWORK DEVELOPMENT

IF continues the development of partnerships with relevant stakeholders to further contribute to the level of knowledge and understanding of Spina Bifida and Hydrocephalus. 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 Spina Bifida and Hydrocephalus worldwide for improving the infrastructure for prevention and treatment.

IF IS A MEMBER OF:

- **European Disability Forum (EDF)**
- **European Patients' Forum (EPF)**
- **European Organisation for Rare Diseases (EURORDIS)**
- **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)
- United Nations Children's Fund (UNICEF)
- United Nations Economic and Social Council (UN ECOSOC)
- 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 AT A GLANCE

2020
SNAPSHOT

COMMUNICATIONS ACTIVITIES - DATA

6.583
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3 Videos
949 Views

288
Followers

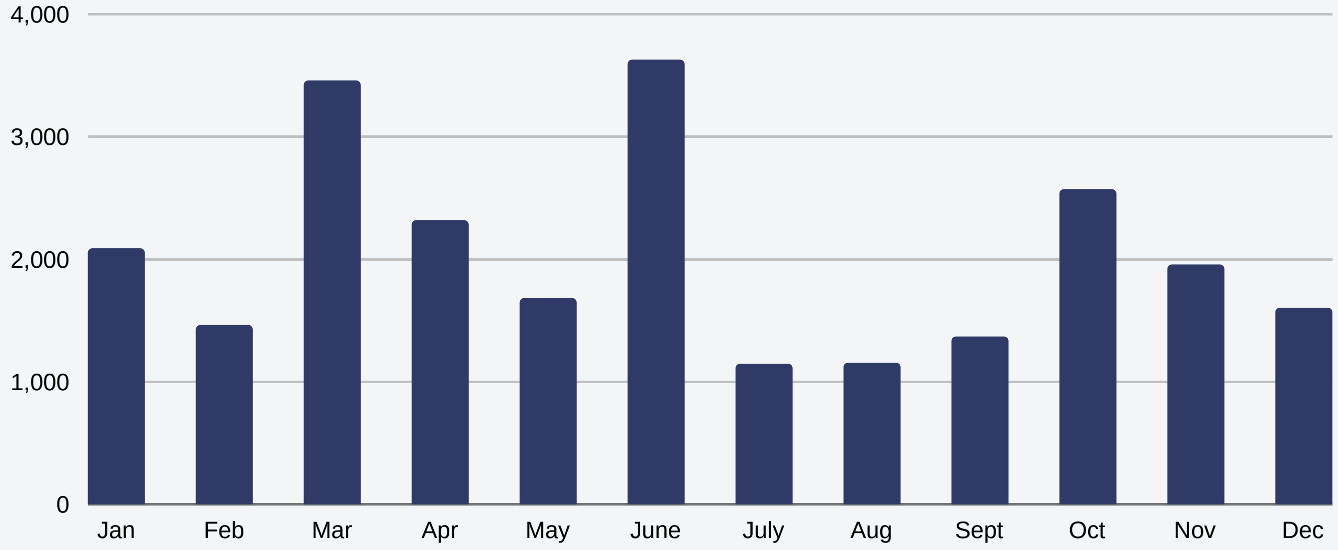
http://

23.361
Visitors

mailchimp

12 Newsletter
12 Members' Voice

Visitors on www.ifglobal.org



2020
SNAPSHOT

COMMUNICATIONS ACTIVITIES - POSTS

IF Global Prevention Initiative

Publié par Renée Jopp
16 juin 2020 ·

Today, from 2.30-4PM, an #IFGPI webinar will take place on #WomensHealth, neural tube defects prevention and the COVID-19 climate, with a focus on #Europe. Respected speakers from organisations such as the World Health Organization and EUROCAT will join us.

Participation is free, but registration is required: https://surveymonkey.com/r/MR958RZ

Women's Health, NTD Prevention and the COVID-19 climate

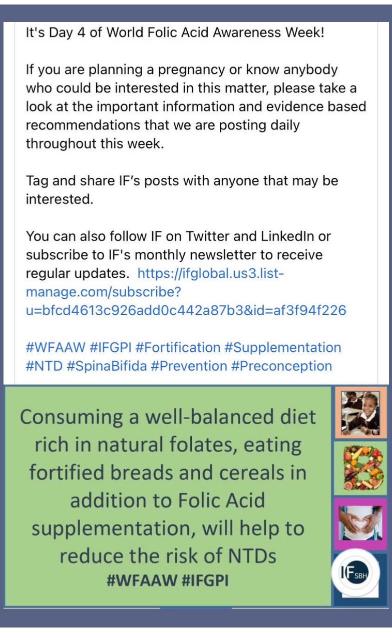
16 June 2020
2.30pm-4pm CET

Women's Health Literacy and the IFGPI (Moderator)
Martine Austin, IF Programme Manager Global Prevention

NTD in Europe and the role of Eurocat
Professor Joan Morris, Scientific Leader of Eurocat & Professor of Medical Statistics

Importance of optimum nutrition for women of childbearing age
Ursula Arens, Independent Nutrition Consultant Writer

Parental mental health and well-being during the COVID-19 pandemic
Dr Neerja Chowdhary, Department of Mental Health and Substance Use In WHO



It's Day 4 of World Folic Acid Awareness Week!

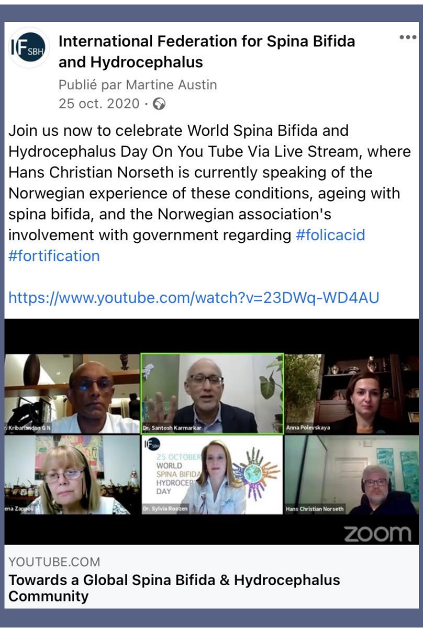
If you are planning a pregnancy or know anybody who could be interested in this matter, please take a look at the important information and evidence based recommendations that we are posting daily throughout this week.

Tag and share IF's posts with anyone that may be interested.

You can also follow IF on Twitter and LinkedIn or subscribe to IF's monthly newsletter to receive regular updates. https://ifglobal.us3.list-manage.com/subscribe?u=bfcd4613c926add0c442a87b3&id=af3f94f226

#WFAAW #IFGPI #Fortification #Supplementation #NTD #SpinaBifida #Prevention #Preconception

Consuming a well-balanced diet rich in natural folates, eating fortified breads and cereals in addition to Folic Acid supplementation, will help to reduce the risk of NTDs
#WFAAW #IFGPI



International Federation for Spina Bifida and Hydrocephalus

Publié par Martine Austin
25 oct. 2020 ·

Join us now to celebrate World Spina Bifida and Hydrocephalus Day On You Tube Via Live Stream, where Hans Christian Norseth is currently speaking of the Norwegian experience of these conditions, ageing with spina bifida, and the Norwegian association's involvement with government regarding #folicacid #fortification

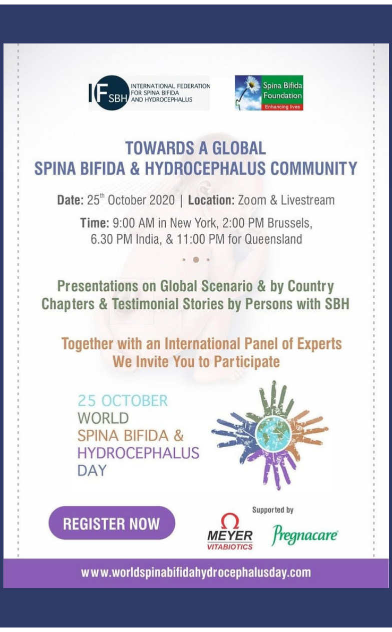
https://www.youtube.com/watch?v=23DWq-WD4AU

YOUTUBE.COM
Towards a Global Spina Bifida & Hydrocephalus Community

International Federation for Spina Bifida and Hydrocephalus

Publié par Verónica Fernández
23 oct. 2020 ·

Access to healthcare is key, especially in COVID-19 times: governments have to eliminate any physical or attitudinal barriers and prevent discriminatory denial of health care or health services on the basis of disability, in line with Art. 25 of the UN CRPD
#WSBHD20



TOWARDS A GLOBAL SPINA BIFIDA & HYDROCEPHALUS COMMUNITY

Date: 25th October 2020 | **Location:** Zoom & Livestream

Time: 9:00 AM in New York, 2:00 PM Brussels, 6.30 PM India, & 11:00 PM for Queensland

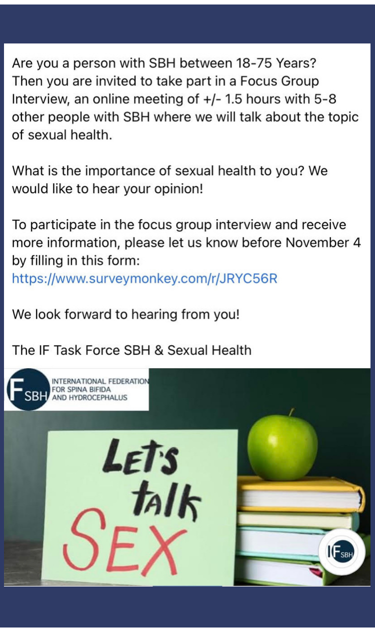
Presentations on Global Scenario & by Country Chapters & Testimonial Stories by Persons with SBH

Together with an International Panel of Experts We Invite You to Participate

REGISTER NOW

Supported by

www.worldspinabifidahydrocephalusday.com



Are you a person with SBH between 18-75 Years? Then you are invited to take part in a Focus Group Interview, an online meeting of +/- 1.5 hours with 5-8 other people with SBH where we will talk about the topic of sexual health.

What is the importance of sexual health to you? We would like to hear your opinion!

To participate in the focus group interview and receive more information, please let us know before November 4 by filling in this form: https://www.surveymonkey.com/r/JRYC56R

We look forward to hearing from you!

The IF Task Force SBH & Sexual Health

International Federation for Spina Bifida and Hydrocephalus

Publié par Verónica Fernández
25 oct. 2020 ·

People with spina bifida and/or hydrocephalus are disproportionately affected when health, social and education services are shut down. States must do better and formulate inclusive and human rights-based emergency plans and guidelines
#WSBHD20

Folic Fortification is an accessible and cost-effective means to improve folate status at population level with no significant pass through costs to consumers. Individuals with Spina Bifida and Hydrocephalus are key to helping increase understanding and demand for these products

#WFAAW #IFGPI

FINANCIAL REPORT

REPORT OF THE AUDITOR ON THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31-12-2020 ADDRESSED TO THE GENERAL MEETING OF "INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS" (Cellebroersstraat 16 —1000 Brussels).

In accordance with the assignment by the Board of Directors, we report to you on the performance of the audit mandate which has been entrusted to us.

We have audited the financial statements for the year ended 31-12-2020, prepared under the responsibility of the board of directors of the federation, which show a balance sheet total of € 884.123,44 and a loss for the year of € 3.002,82.

UNQUALIFIED AUDIT OPINION ON THE FINANCIAL STATEMENTS

Our audit was planned and performed to obtain reasonable assurance about whether the financial statements are free of material misstatement.
Federation officials have responded clearly to our requests for explanations and information.

On a test basis, we have examined the justification for the amounts included in the annual accounts. We have assessed the accounting policies, the significant accounting estimates made by the federation and the overall financial statement presentation.

We believe that our audit provides a reasonable basis for our opinion.
In our opinion, taking into account the legal and regulatory requirements applicable in Belgium, the financial statements for the year ended 31/12/2020 give a true and fair view of the federation's assets, liabilities, financial position and results of operations.

ADDITIONAL CERTIFICATIONS AND INFORMATION

We supplement our report with the following certifications and information which do not modify our audit opinion on the financial statements:

- Without prejudice to formal aspects of minor importance, the accounting records were maintained in accordance with the legal and regulatory requirements applicable in Belgium.

- Otherwise, we do not have to report to you any transactions undertaken or decisions made in violation of the bylaws or the articles of the Law on Non-Profit Organisations.

Ninove, March 25th 2021
Christel de Nul
Certified Accountant

BALANCE SHEET

Assets (€)	31-Dec-2020	31-Dec-2019
TANGIBLE ASSETS	650.79	2,393.29
IT & office supplies	10,794.39	10,794.39
Depreciations IT & office supplies	-10,794.39	-9,051.89
Office furniture	3,577.83	3,577.83
Depreciations office furniture	-3,577.83	-3,577.83
Cautions	650.79	650.79
AMOUNTS RECEIVABLE	14,356.83	200,842.93
Debtors	14,356.83	3,466.82
Invoices to make	0.00	0.00
Advances	0.00	0.00
Dubious debtors	0.00	0.00
Depreciations debtors	0.00	0.00
Taxes receivable	0.00	0.00
Social charges receivable	0.00	776.02
Subsidies to receive	0.00	59,142.20
Projects current accounts	0.00	676.83
Divers to receive (salary)	0.00	0.00
Child Help current account	0.00	75,173.82
Child Help Int. current account	0.00	61,607.24
BANK & CASH ACCOUNTS	868,794.43	344,640.61
KBC - accounts	37,406.33	152,224.63
KBC - accounts saving	831,388.10	192,415.98
TRANSIT ACCOUNTS	321.39	511.17
Deferred charges	321.39	511.17
Accrued income	0.00	0.00
TOTAL ASSETS	884,123.44	548,388.00

BALANCE SHEET

Liabilities (€)	31-Dec-2020	31-Dec-2019
RESERVES	196,415.06	199,417.88
Funds of IF	199,417.88	196,665.72
Interim profit-loss bookyear	-3,002.82	2,752.16
PROVISIONS	3,088.91	3,088.91
Provision return subsidies	0.00	0.00
Provision relocation	3,088.91	3,088.91
AMOUNTS PAYABLE	67,258.24	36,075.13
Suppliers	29,725.75	24,795.53
Invoices to be received	0.00	0.00
Taxes payable	0.00	1,548.00
Social charges payable	0.00	0.00
Salary's payable	0.00	0.00
Provision holiday fee	6,785.39	9,731.60
Divers payable (rent)	14,040.00	0.00
Child Help account	23.81	0.00
Subsidies EU to return	16,683.29	
TRANSIT ACCOUNTS	617,361.23	309,806.08
Account charges	17,619.97	0.00
Deferred income	599,741.26	309,806.08
TOTAL LIABILITIES	884,123.44	548,388.00

PROFIT AND LOSS

INCOME (€)	649,169.92
General income	643,102.98
Membership fees	8,107.08
Donations	3,694.16
Contribution Bühler AG (FFI)	138,474.43
Contribution Vitabiotics	19,768.55
Contribution Mühlenchemie (Smarter Futures)	50,000.00
Contribution Nouryon	50,000.00
Contribution Child Help organisations	7,700.00
Subsidies Smarter Futures (through Global Alliance for Improved Nutrition)	185,144.26
Subsidies European Commission - Rights, Equality and Citizenship Programme	216,559.47
Deferring income to 2021	-36,344.97
Diverse recuperation	684.48
Financial Income	5,382.46
RESULT	-3,002.82

PROFIT AND LOSS

ALL COSTS (€)	652,172.74
General costs	379,010.54
Housing costs (rent, energy, cleaning)	15,263.94
Office supplies	1,106.25
Publications (documentation, etc.)	12,122.68
Communications costs (website, telephone, postal)	7,077.19
Membership of associations	1,306.33
Bookkeeping	6,456.36
Audit	1,936.00
Translation costs	1,039.95
Social and medical secretariat	5,537.29
Insurance	944.68
Consultants - Human Rights	9,508.75
Consultants - Food Fortification (Smarter Futures)	167,669.36
Consultant - Recruitment	6,050.00
Official documents (visa)	98.92
Travel costs	24,766.53
Accommodation and subsistence	7,014.40
Conferences - Workshops	4,159.20
Projects: medical material and treatment	
Projects: salaries	106,952.71
Salaries	264,924.52
Depreciations and provisions	1,742.50
Taxes and financials costs	6,495.18

CONTACT DETAILS

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

IFSBH INTERNATIONAL FEDERATION
FOR SPINA BIFIDA
AND HYDROCEPHALUS