



INTERNATIONAL FEDERATION  
FOR SPINA BIFIDA  
AND HYDROCEPHALUS



# ANNUAL REPORT

2019

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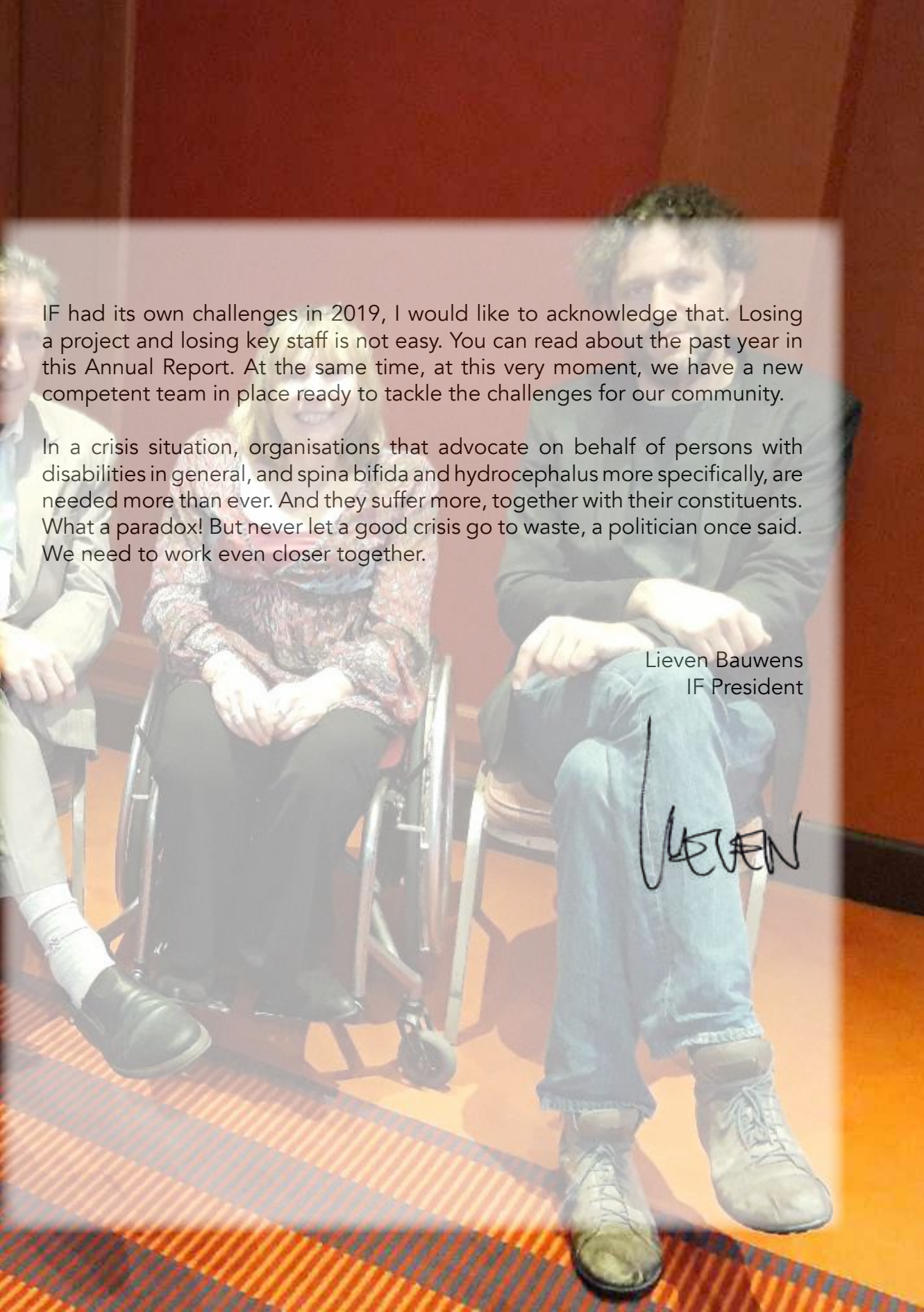
# FOREWORD

Dear members, partners and friends,

I am writing this from the confinement and comfort of my home in the midst of a global pandemic. I literally made it back right on time, as I returned from Kenya the day before Belgium was locked down and all traffic into the country was stopped. We might have had a few scares in the (recent) past, but the COVID-19 one triggered quite a response. In this global world, where all is interconnected, dominos started to fall, locking down millions in their homes in almost all countries. Rich or poor, white or black, left or right. In the beginning it seemed that it did not matter. If I look at the sky today, I cannot see any contrails of planes. In Venice, canals cleared out and fish returned. New Delhi saw the sky again as the smog disappeared.

But, as the lockdown continued, who you are and where you start from, seems to matter more and more. Mortality to Covid-19 is heavily correlated with poverty. As a representative of the spina bifida and hydrocephalus community, I followed a discussion on triage if the person in need of treatment has a disability: a person without a disability gets priority over a person with a disability if a choice, for example for a scarce ventilator, needs to be made. As an advocate for the Convention on the Rights of Persons with Disabilities, I witnessed the inability of governments to care for their citizens with disabilities in this crisis. Children in need of an urgent shunt revision do not make it to the hospital in time. Elective procedures are postponed for months, resulting in preventable co-morbidities.

Unfortunately, this is only going to be the beginning. A global economic crisis will unfold. And we know that a crisis like that hits those in need most. Social programmes are the first to be hurt. Countries with weak social safety nets make people with disabilities suffer most.



IF had its own challenges in 2019, I would like to acknowledge that. Losing a project and losing key staff is not easy. You can read about the past year in this Annual Report. At the same time, at this very moment, we have a new competent team in place ready to tackle the challenges for our community.

In a crisis situation, organisations that advocate on behalf of persons with disabilities in general, and spina bifida and hydrocephalus more specifically, are needed more than ever. And they suffer more, together with their constituents. What a paradox! But never let a good crisis go to waste, a politician once said. We need to work even closer together.

Lieven Bauwens  
IF President





# ABOUT IF

[www.ifglobal.org/about-us/](http://www.ifglobal.org/about-us/)





# WHAT IS IF?

The **International Federation for Spina Bifida and Hydrocephalus** (IF) is a global network representing people with Spina Bifida and Hydrocephalus (SBH) and their families. Founded in 1979, it is now a professional organisation represented on all continents, with unique and expert knowledge of SBH, treatment and care, prevention measures and the human rights & right to health of people with SBH throughout the lifespan.

## MISSION

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 by primary prevention through improving maternal health literacy, raising awareness, political advocacy, research, community building, and human rights education.

## VALUES

**Human rights:** promotion & protection of human rights of people with SBH in accordance with the UN Convention on the Rights of Persons with Disabilities (UN CRPD) 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 & durable relations with international, regional & national bodies, NGOs, professional associations & other stakeholders who share our vision & goals

**Transparency & accountability:** we work in a transparent & inclusive way, fully accountable to our members, donors & external stakeholders.





# THE BOARD



**Lieven Bauwens**  
IF President  
Belgium



**Elena Zappoli**  
Vice President  
Argentina



**Papatya Alkan Genca**  
Secretary  
Turkey



**Cato Lie**  
Treasurer  
Norway



**Emma Suardiaz**  
Spain



**Aziza Mustafa  
Elnaeema**  
Sudan



**Rasmus Isaksson**  
Sweden



**Giulia Bizzotto**  
Italy



**Frantisek Horn**  
Slovakia

During the 2019 General Assembly (October 26, Ghent, Belgium) IF held elections for new Board members and IF's President. After 15 years working as Secretary General, Lieven Bauwens was elected as the new President of IF. He took over from Margo Whiteford who has been IF's President for 9 years and to whom the whole SBH community is very thankful!

Two IF Board members were re-elected for another three year period: Papatya Alkan Genca from Turkey and Aziza Mustafa Elnaeema from Sudan. Also, we welcome two new Board members: Rasmus Isaksson, representing IF member organisation Spin-Off (Sweden) and Giulia Bizzotto representing IF member organisation ASBI (Italy).

# THE TEAM



**Dr. Sylvia Roozen**  
Secretary General



**Renee Jopp**  
Information Officer



**Carmen Clemente**  
Communications  
Coordinator



**Verónica Fernández**  
Administration Officer



**Hildur Kristjana**  
EU Policy Officer



**Martine Austin**  
Programme Manager  
Global Prevention



**Anna Verster**  
Senior Adviser on Food  
Fortification

We said goodbye to **Janina Arsenjeva** and **Katalijne Van Diest**, who worked for IF for more than 5 and 10 years respectively. We're really thankful for all their contributions to the SBH community. **Giuseppe Martone** finished his European Volunteer Service period within the communication team at IF in July 2019, it was a pleasure to work with him.

We welcomed **Athina Giannoutsou**, our great and beloved EU Policy Officer, in 2019 and we had to say goodbye to her in April 2020. She worked very hard to push IF forward with regard to policy actions and visibility.

Also, some good news is the arrival of three new colleagues: **Verónica Fernández** as the new IF Administration Officer, who joined the team in April 2020, **Sylvia Roozen**, who joined IF in June 2020 as the new IF Secretary General and **Hildur Kristjana Onnudottir**, joining in July 2020 as IF EU Policy Officer!

Exciting times for IF!



# GLOBAL EXPERTS PANEL



**Margo Whiteford**  
Chair



**Amy McPherson,**  
Social Inclusion



**Anne Molloy**  
Causes



**Benjamin Warf**  
Services and Care



**David Nolan Morrisey**  
Human Rights



**Richard H. Finnell**  
Genetics

In 2019, the GEP contributed regularly along the year to IF's workplan and specifically to two IF responses for the UN Special Rapporteur on the Rights of Persons with Disabilities, Ms. Catalina Devandas-Aguilar:

- the IF response to a questionnaire on bioethics and disability published in September 2019
- the IF response to the consultation on the rights of older persons with disabilities published in April 2019

## Members and consultants of the Global Experts Network

Ronald Afidra, FFI Africa Network Coordinator / Quentin Johnson, FFI Training&Technical Support Coordinator / Femke Bannink, Senior Advisor on Inclusive Education / Richard Bransford, surgeon, MD, FACS / Myleen Christiaens, spina bifida nurse / Kordelia Fischer-Borchert, community-based rehabilitation / Philippe Gillis, paediatrics & tropical medicine / Helen Healy, life skills & translation / Marisol Hernández, IF liaison Buenos Aires / Koen Sevenants, senior advisor, Dev Cooperation Asia / Carla Verpoorten, neuro-paediatrician/Patrick De Vlioger, anthropology & disability / Wouter De Groote, rehabilitation, psychiatrist / Joanne Maxwell, life skills & transition / Rebecca Opetsi Alitsi, CRPD/SDGs Africa



**HOPE-SBH**

HOPE - SPINA BIFIDA  
& HYDROCEPHALUS  
UNTAR BAKRAF






# OUR

# MEMBERS

[www.ifglobal.org/members/](http://www.ifglobal.org/members/)

A group of approximately ten people are seated around a long table covered with a dark blue cloth in a meeting room. The room has dark wood-paneled walls and a red carpet. The participants are dressed in business casual attire. Some are looking towards a man in a white shirt who is speaking, while others are looking at documents or listening. The lighting is warm and focused on the table area.





## **AFRICA**

Algeria - l'Association des Parents et Malades Spina Bifida Béjaia (APMSBB)  
Egypt - Waad Spina Bifida 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  
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  
Zambia - Zambia Association for Hydrocephalus and Spina Bifida (ZAHSB)

## **AMERICAS**

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 (SBA)

## **ASIA & AUSTRALIA**

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 Organisation from Kazakhstan  
Malaysia - Spina Bifida Association Malaysia (SIBIAM)  
Mongolia - Mongolian Spina Bifida Foundation "Maral Angel"  
South Korea - Korea Spina Bifida Patient Association  
Taiwan - Taiwan Spinal Bifida Association

In 2019, IF welcomed 3 new members from different continents



## EUROPE

Austria - Spina Bifida und Hydrocephalus Österreich (SB&HÖ)  
Belgium - Association Spina Bifida Belge Francophone  
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  
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 - 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 - Latvijas spina bifida un hidrocefālijas biedrība (LSBH)  
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 - Asociația Română de Spina Bifida și Hidrocefalie  
Russia - GAOORDI (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  
Spain - Asociación Madrileña de Espina Bífida e Hidrocefalia (AMEB)  
Spain - Asociación Murciana de Padres e Hijos con Espina Bífida  
Spain - Federación Española de Asociaciones de Espina Bífida e Hidrocefalia  
Sweden - Spin-Off  
Sweden - Rörelsehindrade Barn & Ungdomar  
Switzerland - Schweizerische Vereinigung zugunsten von Personen mit Spina Bifida und Hydrocephalus (SBH)  
The Netherlands - BOSK Work Group Spina Bifida & Hydrocephalus  
Turkey - Türkiye Spina Bifida Derneği  
UK - Spina bifida • Hydrocephalus • Information • Networking • Equality (Shine)  
Ukraine - Parents Association for Spina Bifida and Hydrocephalus 'Lights of Spirit'



# NETWORK DEVELOPMENT

[www.ifglobal.org/our-work/network-development/](http://www.ifglobal.org/our-work/network-development/)





## **IF IS MEMBER OF:**

- European Disability Forum (EDF)
- European Patients' Forum (EPF)
- The European Organisation for Rare Diseases (EURORDIS)
- Rare Diseases International (RDI)
- International Disability and Development Consortium (IDDC)
- Partnership for Maternal, Newborn and Child Health (PMNCH)
- International Disability Alliance (IDA)

## **IF HAS AN ONGOING COLLABORATION WITH:**

- The United Nations Children's Fund (UNICEF)
- United Nations Economic and Social Council (UN ECOSOC)
- World Health Organisation (WHO)
- European Concerted Action on Congenital Anomalies and Twins (EUROCAT)
- European Reference Network ITHACA

## **IF's PARTNERS IN LOW AND MIDDLE INCOME COUNTRIES (LMIC):**

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



## **IF GETS FINANCIAL CONTRIBUTION FROM:**

- European Union (EU) - Rights, Equality and Citizenship programme of the European Union
- Bühler
- Nouryon
- Mühlenchemie
- Vitabiotics Pregnacare
- The Global Alliance for Improved Nutrition (GAIN)
- Child-Help International, Child-Help Belgium and Child-Help the Netherlands
- NORAD, Norway through the Ryggmargsbrokk- og hydrocephalusforeningen (Norwegian Association for SBH)
- Ministry of Foreign Affairs of the Netherlands, through GAIN
- DFID, UK through International Disability Alliance
- Nutrition International

## **IF COLLABORATES ON PROJECTS WITH:**

- Atlas Alliance, Norway
- Food Fortification Initiative (FFI)
- Helen Keller International (HKI)
- Nouryon
- Mühlenchemie
- Boston Children's Hospital
- March of Dimes
- University of Toronto, Sunnybrook Health Sciences Centre
- CURE International and CURE Hydrocephalus and Spina Bifida
- CDC's National Center on Birth Defects and Developmental Disabilities
- University of Ghent

DATA

EDUCATION  
- INCLUSIVE

PRE

# OUR WORK 2019

ACCESS  
TO HEALTH

BUILDING  
ORG'S IN  
COUNTRY

HUMAN  
RIGHTS

ACCESS  
(even)

VENTION

MINATION

S&H  
ALL  
RES

STABILITY  
(BASE CASE)

Develop  
New  
Genes

Develop  
New  
Genes

Develop  
New  
Genes

Develop  
New  
Genes

Develop  
New  
Genes

Develop  
New  
Genes





# CALENDAR

## JANUARY

- IF celebrates 3rd World Folic Acid Awareness Week
- IF Survey on sexuality & body awareness
- IF Prevention Consultancy Clinic: announcement!
- IF, HKI and FFI renew the Smarter Futures partnership with Nouryon

## FEBRUARY

- IF launches its World Birth Defects Day toolkit
- IF Secretary General advocates for rare diseases at UN
- #ShowYourRare for Rare Disease Day 2019!

## MARCH

- Folic acid distribution in schools, Uganda: SHAU, Norad, RHF
- IF Membership Guide 2019
- 'They Give Him a Chance': a new study on inclusive primary education in Uganda
- European Elections 2019: IF starts advocacy campaign

## APRIL

- 'SKI for ALL' project by ASBI: info project
- IF submission on the rights of older persons with disabilities
- Welcome to Athina, IF's new European Policy Officer!
- World Health Day – We need Universal Health Coverage
- IF joins EUROLINKCAR Action Advisory Panel

## MAY

- Lieven Bauwens re-elected in EURORDIS Board
- EU workshop in Belgrade, Serbia
- IF response to UN Special Rapporteur on medical education
- IF Open Letter: violation of the rights of young people with disabilities in institutional care

## JUNE

- Work-Life Balance Directive adopted by the Council of the European Union
- IF advocates for birth registration at 12th COSP
- IF Survey: What does ageing with SBH mean to you?

## JULY

- IF joins Global WHO Birth Defects Technical Working Group
- UK consultation on proposal to introduce mandatory fortification of flour with folic acid
- Launch of World Spina Bifida & Hydrocephalus Day: 'The Full Picture' campaign

## AUGUST

- Launch and information about IF & ASBI Youth Conference on Sexuality and Body Awareness
- IF 4th 'MyRights' Youth Training in Estonia

## SEPTEMBER

- IF joins EDF statement on passengers' rights
- IF analysis on the new European Commission
- IF response to UN Special Rapporteur questionnaire on bioethics and disability

## OCTOBER

- World Spina Bifida and Hydrocephalus Day 2019 #TheFullPicture campaign
- EU workshop II, celebration of IF 40th anniversary and approval of new members and Board members at IF
- IF & ASBI Youth Conference on Sexuality and Body Awareness

## NOVEMBER

- World Toilet Day: experiences from the spina bifida community
- European Days of Persons with Disabilities 2019: launch of SkixAll guidelines

## DECEMBER

- IF participation at the European Days of Persons with Disabilities event in Brussels

# WSBHD 2019

## #TheFullPicture campaign

[www.worldspina bifidahydrocephalusday.com/2019-theme](http://www.worldspina bifidahydrocephalusday.com/2019-theme)

In 2019 IF had a double celebration: its **40th anniversary** and the **World Spina Bifida and Hydrocephalus Day** (WSBHD) on October 25. Therefore, we invited the entire SBH community to join us in this double and special celebration. IF wanted to look back and get some good energy from all the work done together with our members and partners so we launched our "The Full picture" campaign!

Some of IF's members shared testimonies about their life with SBH and their reflections on how IF has supported them along their journey.



"IF helps people to overcome their challenges connected to spina bifida and to know more about the condition. One thing that I learnt is that you can do so many positive things with this condition for me and other people who are facing SB. I accepted many challenges at a very early age with help of my parents, family member"

Armughan Ali, Pakistan



"The IF training on UNCRPD, advocacy and capacity building is very useful, it gives us very practical advices and ideas. On the other hand, the other countries' example is very motivating and valuable. I came home from the training in Estonia this year with a lot of new ideas how to proceed with our advocacy. I believe that soon we will have some visible results"

Albena Marinova, Bulgaria



A special contribution has come from the 3 presidents of IF, who wanted to share their memories and wishes. Thank you Björn Rundström, founder of IF, Pierre Mertens and Margo Whiteford for giving us the opportunity to interview you.



"I was sent to Europe to see if we could find parent organisations. We found some and invited them to a meeting in Stockholm. That was in 1979 and it was the first meeting as IF"

Björn Rundström, founding President of IF



"We have so many examples of how meaningful a life with SBH can be... It is important for parents to see a future for their children or else they will not invest in their child"

Pierre Mertens, former IF President



"I think the fact that IF has brought so many countries together is the biggest achievement. They also got things on the political agenda such as prevention of spina bifida using folic acid through fortification or supplementation."

Margo Whiteford, former IF President

Material produced:

- Guidelines document
- IF logo anniversary
- Special newsletters
- Articles on IF website
- Webpage in WSBHD website



Take a look at [IF's Facebook album](#) to read all the written testimonies and our [YouTube channel](#) to watch the video-testimonies. As every year, we updated our special website: [www.worldspinabifidahydrocephalusday.com](http://www.worldspinabifidahydrocephalusday.com)

Thank you all for your support, especially to our members for sharing the call within their organisation, resulting in unique contributions!

# PRIMARY PREVENTION

[www.ifglobal.org/our-work/prevention/](http://www.ifglobal.org/our-work/prevention/)

## ADVOCACY

### IF Global Prevention Initiative (IFGPI)

- World Folic Acid Awareness Week (WFAAW) in January 2019: with the support of Vitabiotics Pregnacare, IFGPI ran a great social media awareness campaign by publishing posters with key messages, banners for social media, the WFAAW toolkit, launching the renewed leaflet on folic acid '[What every woman needs to know before becoming pregnant](#)' in English and sending a press release.
- 28th October 2019 marked the 3rd anniversary of the IFGPI. We sent out a press release to promote the anniversary. There was an increase of followers on the IFGPI Facebook page and we also published a press release to mark the event.
- Folic Acid leaflet: after publishing the EN version of the new leaflet on folic acid during the WFAAW 2019, we launched a call to our members to translate the document and we received contributions from our Spanish, Italian, French member organisations.



### ACIDO FOLICO

Ciò che ogni donna deve sapere prima di una gravidanza



### ACIDE FOLIQUE

Ce que toutes les femmes doivent savoir AVANT d'être enceintes



### ÁCIDO FÓLICO

Lo que toda mujer necesita saber antes de quedar embarazada

- IF Secretary General Lieven Bauwens represented IF in Geneva to lead a side event organised by the Rare Diseases International (RDI) at the World Health Organization (WHO) 72nd World Health Assembly (WHA72). IF's main points were: the importance of prevention and the need for early intervention when it comes to SBH and the need for data.

- Womens' Health Wednesday campaign is now an established weekly social media poll on Twitter and the IFGPI Facebook page. The polls educate on topics of women's health concerns (including management of non-communicable disease), especially around topics of neural tube defects and hydrocephalus prevention and healthy pregnancy and preconception, and raise awareness of the importance of health literacy for all women. We continued to learn more about levels of health literacy, topics where there are gaps in knowledge and assess need, to build-in the IFGPI prevention strategy.
- IF Response to the consultation launched by the UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. IF focused on the key role of medical education in the primary prevention of neural tube defects and with regard to care for persons with SBH.

## LEARNING

### Folate Task Team (FTT)

- Development of two 'knowledge briefings' in partnership with Nutrition International and The Folate Task Team focussing on prevention and policy in low and middle-income countries (with input from IF members) : 'Preventing Neural Tube Defects In Low And Middle-Income Countries and the Importance of Representative Organisations' and 'The Policy Environment For Folic Acid Interventions To Prevent NTDs: Understanding Supplementation And Laying The Groundwork For Fortification'





## Smarter Futures (SF)

- During the Smarter Futures' Steering Group meeting in Hamburg in February 2019, IF Secretary General Lieven Bauwens led a discussion on the extremely high rates of neural tube defects (NTDs) Ethiopia is experiencing. Current fortification efforts, which provide folic acid (along with other nutrients) through wheat flour, have only been voluntary to date with a standard approved by the government in 2018. The group discussed the current recommendation by Dr. Godfrey Oakley to add folic acid to Ethiopia's iodized salt.
- Anna Verster, IF Senior Adviser of Food Fortification, participated in the EU workshop in Belgrade



## Prevention Consultancy Clinics

- 2019 saw the launch of the IFGPI Prevention Consultancy Clinics. The aim of the clinics is to increase our understanding and knowledge of country specific NTD incidence, prevention climate and barriers to prevention in order to best inform the direction of our prevention activity at country level. Members are invited/welcome to listen in to clinics involving members from different countries in order to learn from their successes, challenges and experiences. Country Profiles have been created for participating countries, and are developed on an ongoing basis.

## COMMUNITY BUILDING

- Prevention Consultancy Clinics with members: The clinics took place in a private group call online where our members raised their concerns and issues and let us know where they needed support from IF when it comes to primary prevention. Members that have seen links between their own situations and those of another organisation have shared their knowledge both within the clinics, and have also gone on to support one another externally.
- Renewal partnership with Nouryon: 2019 marks the 10-year anniversary of the Smarter Futures partnership in which Nouryon collaborates with the International Federation for Spina Bifida and Hydrocephalus, Helen Keller International, and the Food Fortification Initiative to improve and increase the availability of fortified wheat, maize flour and rice that meets quality and nutrition standards in Africa.
- IF Secretary General Lieven Bauwens has been officially appointed as a member of the Global WHO Birth Defects Technical Working Group (BD TWG). One of the tasks of the BD TWG is to provide advice to the World Health Organization (WHO) in connection with the development and dissemination of tools for monitoring of birth defects.

### OUR MEMBERS' ACHIEVEMENTS ON PREVENTION

- HOPE-SBH association in Ethiopia: great work on awareness about folic acid through actions such as their campaign 'Back to Bake' (reaching thousands of women); holding a press conference attended by TV, radio and independent social media journalists (led by HOPE-SBH's Dir. Beza Beshah, Dr Abrham from the Ministry of Health and Dr Mersha, a senior neurosurgeon).
- SHA-U association in Uganda: consolidated food fortification advocacy package, PULL (in partnership with IF, the Ministry of Health, GAIN/ENABLE, FFI and other stakeholders) to create awareness and demand for procurement and consumption of fortified staples. This was followed by a second phase, PULL 2.
- Association Nationale Spina Bifida et Handicaps Associés in France: took part in a public hearing offered by the National Ethics Committee to present the association's position on the ethical concerns arising from termination of pregnancies secondary to lack of focus on prevention by folic acid.

# RIGHT TO HEALTH

[www.ifglobal.org/our-work/right-to-health/](http://www.ifglobal.org/our-work/right-to-health/)

## ADVOCACY

### At EU level

IF strengthened its policy work at EU level and those efforts have been reflected in all the actions undertaken along 2019:

- **Raising awareness among our members towards European Elections:** IF created a leaflet and infographic explaining what the EP election is and why this is an important event. IF organised several meetings between July - October with MEPs, political advisors and administrators from several EP Committees to re-establish a network of pro-MEPs on disability rights and especially on spina bifida and hydrocephalus.
- **Open letter on the violation of the rights of young people with disabilities in institutional care:** after the reporting of the Spina Bifida and Hydrocephalus Association of Romania, IF wrote an open letter addressed to the Romanian government and the authorities working within human and disability rights, calling on them on behalf of young people with disabilities living in Romanian institutions. The open letter is also supported by the Romanian Association for SBH, the European Disability Forum (EDF), the National Disability Council in Romania and the National Alliance for Rare Diseases in Romania.
- **IF signed joined statement developed by the European Disability Forum on the rights for passengers with disabilities and in light of the reviewing the Rail Passenger's Rights Regulation**
- With the new European Commission established at the end of 2019, IF prepared an **analysis with all the relevant Commissioners** for the spina bifida and hydrocephalus (SBH) community.
- IF prepared its **recommendations for the post-2020 European Disability Strategy**
- IF endorses **joint statement on the Right to Family of children without parental care**

For more information about IF's advocacy work and news related to Europe, visit: [www.ifglobal.org/news/europe/](http://www.ifglobal.org/news/europe/)



## Working Group on Ageing

In the past years, our members have emphasised the importance of raising awareness about ageing with spina bifida and hydrocephalus (SBH). Due to improved treatment and care, many children born with SBH have grown up, become adults, and are reaching their senior years. At the same time, we know very little about ageing with SBH and its impact on physiology, mental abilities and independence. There is a need to improve our understanding of the lived experience of older persons with SBH, which is why it has become a key objective for our organisation. Therefore, IF has created the Working Group on Ageing with SBH.



In 2019, the Working on Ageing with SBH published:

- **A survey on ageing with SBH** to learn more about the current situation and needs of people ageing with SBH. The survey was translated into English, Dutch/Flemish, French, German, Italian, Norwegian, Portuguese, Romanian, Slovak, Spanish, Swedish and Turkish. The responses will contribute to an exploratory European study on this topic.
- **Initial survey findings:** An overwhelming number of people participated in the survey. We received nearly 650 completed forms, from 26 European countries. As the survey closed on 30 September and all open answers needed to be translated, the full analysis will take place in 2020. Using the survey software, initial findings were presented during the IF EU Workshop In 2019.
- **UN questionnaire on the rights of older persons with disabilities:** In 2019, the United Nations Special Rapporteur on the Rights of Persons with Disabilities, Ms. Catalina Devandas-Aguilar, called for input on a report she was preparing on the rights of older persons with disabilities. With the support of the members of the Working Group, IF sent in a response to the UN questionnaire.

For more information about the working group on ageing, visit:

[www.ifglobal.org/our-work/working-group-on-ageing-with-sbh/](http://www.ifglobal.org/our-work/working-group-on-ageing-with-sbh/)

## Youth Group: project on sexuality and body awareness

Back in mid-2018 a group of young people with SBH started to collaborate with IF to address the most interesting topics for the youth community with SBH. After some discussions, they decided to work on 'sexuality and body awareness of people with SBH', issues that are both surrounded by taboos and stigma. In this way, they built the current youth working group. Along 2019, the youth group developed different projects and activities:

- **Survey on sexuality and body awareness** to build up a solid basis of evidence on what is important for young people with SBH about their sexuality and body awareness in order to continue working on the topic. The survey was available in English, French, Italian, Spanish, Turkish, Montenegrin and Flemish. The survey collected 400 responses! A first general report out of this survey was launched on December 10, UN Human Rights Day.
- **International Youth Conference #LoveSAFe-SBH**. As a wrap up action, the youth group together with IF and its Italian member organisation ASBI, organised an international youth conference to openly discuss key issues: relationships, affectivity and sexuality. The event took place on 5-6 October in Varese (Italy).



For more information about the youth group projects, visit:

[www.ifglobal.org/our-work/youth-group-sexuality-body-awareness/](http://www.ifglobal.org/our-work/youth-group-sexuality-body-awareness/)

# LEARNING

## 4th edition MyRights training

IF organised its 4th edition of the youth training in which the participants learn about the UN CRPD and how to make use of it to claim their own human rights. The training took place in Tallinn, Estonia from 17 to 20 August. Eight young people from Bulgaria, United Kingdom, Turkey, Estonia and Sweden learnt, exchanged ideas and opinions, laughed and worked together during four intensive days. There was an excellent team of trainers:

- 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.
- Rasmus Isaksson, of the Swedish organisation 'Förbundsordförande DHR' and Board member of IF since October 2019



The participants prepared an action plan to tackle a specific issue at local level and present convincing arguments based on the UN CRPD. All the participants developed and presented an advocacy action plan as a final activity of the training, which could be the basis for implementation in their own communities.

[Read the full report of the 4th edition of 'MyRights' training here](#)



# COMMUNITY BUILDING

## European Reference Networks (ERNs)

In 2019, IF has taken the role of secretariat and is also a member of the cross-ERN Working Group Spina Bifida (WG SB) within the ERN ITHACA through its patient representative Ammi Sundqvist and an IF staff member.

In addition, Ammi Sundqvist sits on the ERN-ITHACA Patient Council Board and on the ITHACA Board and Executive Committee. As a result, special attention has been given to spina bifida in the grant application for ILIAD, ERN-ITHACA's proposed patient registry.

Other European experts have been added to the WG SB to work on the revision of the Orphacodes for spina bifida, linking the WG SB activities to Orphanet. Interested European (non-ERN) spina bifida clinicians have been receiving WG SB updates too, and IF's members were able to interact directly with IF's patient representative at the IF Workshop in Ghent during dedicated info and Q&A sessions.

## IF European workshops

- The IF EU Workshop I took place in Belgrade (Serbia) and it had a special focus on prevention and folic acid, sexuality, European elections and the urgent topic of human rights for people living with SBH. Some IF's members had the opportunity to present on different topics: IF Board member Elena Zappoli, presented on the folic acid legislation recently approved in Buenos Aires, Argentina; Sharon Levy from Spina Bifida Hydrocephalus Scotland presented on 'Research, Development and (digital) Innovation'.



- **The IF EU Workshop II took place in Ghent (Belgium)** and it focused on cognitive challenges of persons with spina bifida and/or hydrocephalus. A world café session was organised where the members were divided into 4 groups to discuss and exchange ideas on the following topics: the work of the Working Group on Ageing, IF's Multidisciplinary Care for SBH study, our Sexuality and Body awareness project and the Working Group Spina Bifida within the ERN ITHACA.

In addition to the EU Workshop II, **IF celebrated its 40th anniversary** with its European members and some partners and presented the videos of the IF's former 3 presidents and #TheFullPicture campaign for the 8th edition of the World Spina Bifida and Hydrocephalus Day (WSBHD). IF's Secretary General represented IF at the Child-Help reception to celebrate the 40th anniversary of IF with one of our strongest partners.

## OUR MEMBERS' ACHIEVEMENTS ON RIGHT TO HEALTH

- Association for Spina Bifida and Hydrocephalus South Africa (ASBAH SA) organised a youth work day on sexuality and intimacy. They also have an ongoing programme educating Ambassadors about Spina Bifida and Hydrocephalus.
- Partnership of 2 IF's member organisations: Spina Bifida and Hydrocephalus Bulgaria and the Norwegian Association for Spina Bifida and Hydrocephalus developed and implemented 'Empowered Youth'. It supports children with SBH in developing social skills and experience in advocacy.
- Association Nationale Spina Bifida et Handicaps Associés in France was involved in the writing of national guidelines (PNDS) on urological care of adult patients with spina bifida. They also launched "AlloSBSsanté", a helpline that their members can reach to seek medical advices and second opinions through clinical experts.
- Asociación para Espina Bifida e Hidrocefalia from Argentina organised the fourth Latinoamerican meeting of SBH organisations organisations. It took place in December 2019.
- Turkish Spina Bifida Association participated in the first state report concerning UNCRPD and participated in the 21st session of UN Committee on the Rights of Persons with Disabilities which was held in Geneva on 11-14 March 2019.

# COMMS & SOCIAL MEDIA





Kwena mabe

SPINA BIFIDA, "BU  
AND HYDROCEPHALUS

Spina Bifida



Amada pire tye



Yango:  
CURE children's Hospital

Roco ngolo ki lubo kor.  
AVSI Gulu Regional referral  
hospital, GROW 0783584937.

IF Child Help Uganda.  
0776179984.

0454435273



www.avsi.org



Itinda ki kemp ma ee ki bot IF Child He  
Ngee a



IF is continuously investing time and resources in communication and dissemination activities, as a means to share our values and goals, reaching as many people as possible around the world. IF's website and social media channels have increased views and interactions, and many people find a trusted space there, where they can read about SBH-related news, share their ideas and experiences, and interact with us and other users.

The **World Spina Bifida and Hydrocephalus Day special website** is a great platform in which many people around the world find information about the most important day for the SBH community.

Our communication activities are a huge support in giving the SBH community more visibility, most importantly, by highlighting everything that IF and its members do to improve the quality of life of people living with SBH both in the areas of human rights and primary prevention.



25 OCTOBER  
WORLD  
SPINA BIFIDA &  
HYDROCEPHALUS  
DAY



These are some of the communication activities that we did in 2019:

- For the World Folic Acid Awareness Week (January 7-13), the IF Global Prevention Initiative (IF GPI) created a social media toolkit, banners and messages. By the end of 2019, the IF GPI Facebook page had 410 followers and 63% of people engaged are women, out of which 50% are between 25-34 years old, so the key target group is being reached!

- In 2019 IF continued the weekly Wednesday Women's Health (WHW) polls on our social media platforms, building on the understanding of issues related to preconception care and women's health. This campaign clearly impacted positively on the growth of IF GPI Facebook page mentioned above.
- For the World Toilet Day (November 19) IF launched an awareness campaign on access to toilets and to affordable continence material for people living with spina bifida as a matter of human rights. IF sent a statement to the European Parliament, European Commission and Council asking for a transversal and holistic implementation of the UN CRPD. IF also shared a position paper translated into EN, SW and IT and some of our members from Italy, Uganda, Lithuania and Sweden shared their personal testimonies on the importance of urological and intimate care for all, which was shared through social media for dissemination.
- On October 25, we celebrated the 8th World Spina Bifida and Hydrocephalus Day (WSBHD) and the IF's 40th anniversary. IF launched #TheFullPicture campaign to look back at IF's history and get some input from our members and former presidents. As every year, the WSBHD website was updated!
- IF has been very active on Twitter and Facebook for key events such as the European Day of Persons with Disabilities, World Birth Defects Day, World Human Rights Day and many more!

## SOCIAL MEDIA STATISTICS



WEBSITE: 59.047 page views



YOUTUBE: decreased from 6.132 to 2.825



TWITTER: increased from 2.418 followers to 2.770



FACEBOOK: increased likes from 5.652 to 6.382

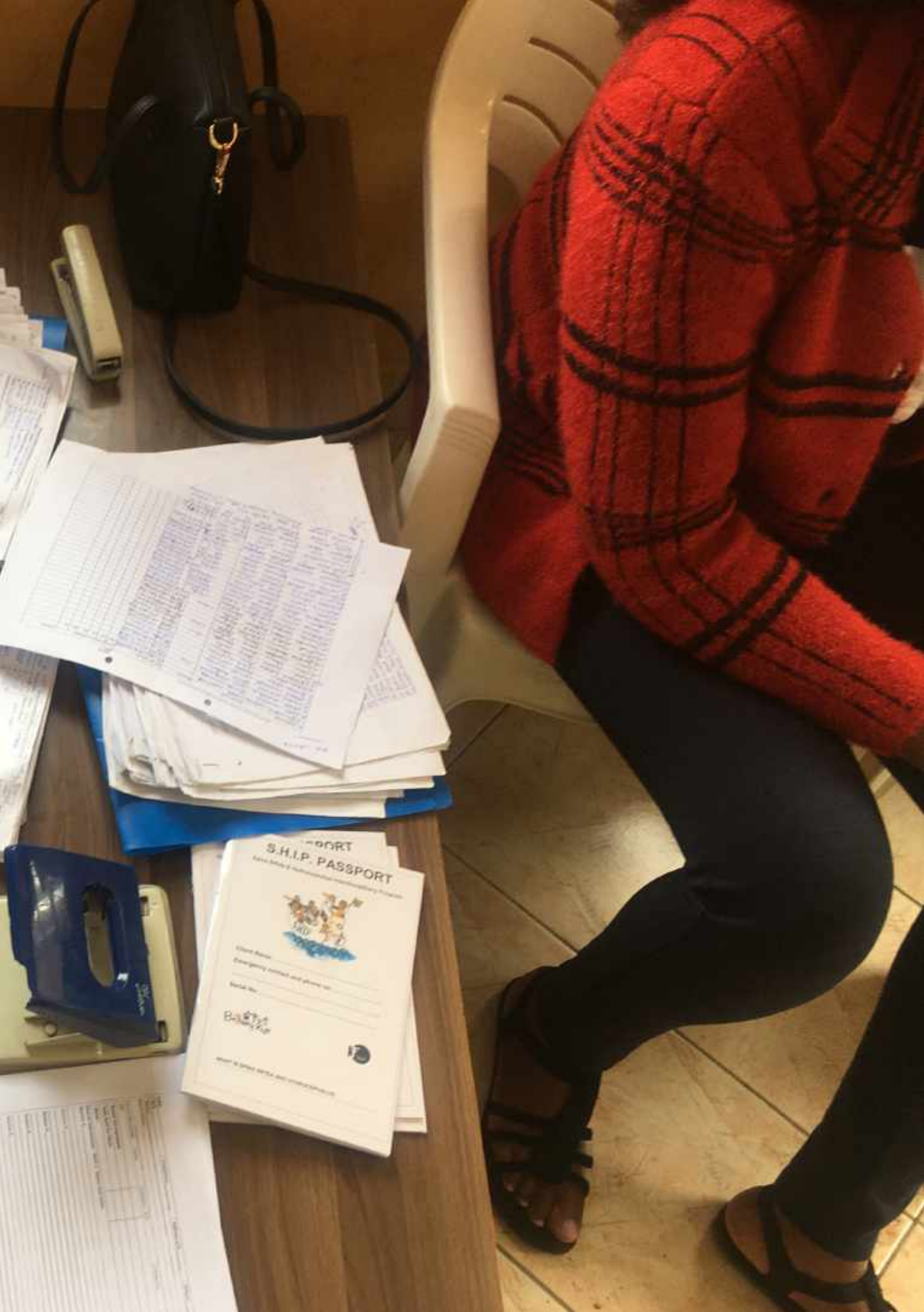


NEWSLETTERS: 12 external, 12 Members' Voices, 2 press releases



# FINANCIAL REPORT





PORT  
S.H.I.P. PASSPORT



Client Name: \_\_\_\_\_  
Emergency contact and phone no: \_\_\_\_\_  
Social No: \_\_\_\_\_

BALTIMORE  
PORT



Member of the Baltimore Harbor and Waterway Authority

REPORT OF THE AUDITOR ON THE FINANCIAL STATEMENTS  
FOR THE YEAR ENDED 31-12-2019 ADDRESSED TO THE  
GENERAL MEETING OF "INTERNATIONAL FEDERATION  
FOR SPINA BIFIDA AND HYDROCEPHALUS"  
(Cellebroerstraat 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 31-12-2019, prepared under the responsibility of the board of directors of the federation, which show a balance sheet total of € 548.388,00 and a profit for the year of € 2.752,16.

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 31/12/2019 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 NonProfit Organisations.

Ninove, April 27th 2020  
Roger De Nul  
Auditor



# BALANCE SHEET

Assets (€)	31-Dec-2019	31-Dec-2018
<b>TANGIBLE ASSETS</b>	<b>2,393.29</b>	<b>4,901.41</b>
IT & office supplies	10,794.39	10,794.39
Depreciations IT & office supplies	-9,051.89	-6,543.77
Cautions	650.79	650.79
<b>AMOUNTS RECEIVABLE</b>	<b>200,842.93</b>	<b>217,437.80</b>
Debtors	3,466.82	5,963.91
Taxes receivable	0.00	452.22
Social charges receivable	776.02	1,033.40
Subsidies to receive	59,142.20	58,858.00
Projects current accounts	676.83	30,623.04
Divers to receive (salary)	0.00	754.13
Child-Help current account	75,173.82	84,030.87
Child-Help Int. current account	61,607.24	35,722.23
<b>BANK &amp; CASH ACCOUNTS</b>	<b>344,640.61</b>	<b>139,589.58</b>
KBC - accounts	152,224.63	45,166.20
KBC - accounts saving	192,415.98	94,415.98
Triodos - accounts	0.00	7.40
<b>TRANSIT ACCOUNTS</b>	<b>511.17</b>	<b>14,918.25</b>
Deferred charges	511.17	1,390.68
Accrued income	0.00	13,527.57
<b>Total assets</b>	<b>548,388.00</b>	<b>376,847.04</b>

Liabilities (€)	31-Dec-2019	31-Dec-2018
<b>RESERVES</b>	<b>199,417.88</b>	<b>196,665.72</b>
Funds of IF	196,665.72	210,181.10
Profit-loss bookyear	2,752.16	-13,515.38
<b>PROVISIONS</b>	<b>3,088.91</b>	<b>3,088.91</b>
Provision relocation	3,088.91	3,088.91
<b>AMOUNTS PAYABLE</b>	<b>36,075.13</b>	<b>52,379.84</b>
Suppliers	24,795.53	19,823.79
Taxes payable	1,548.00	1,611.00
Provision holiday fee	9,731.60	30,824.18
Divers payable	0.00	120.87
<b>TRANSIT ACCOUNTS</b>	<b>309,806.08</b>	<b>124,712.57</b>
Deferred income	309,806.08	124,712.57
Deferred income	124.712,57	0,00
<b>Total liabilities</b>	<b>548,388.00</b>	<b>376,847.04</b>

# PROFIT AND LOSS

<b>INCOME (€)</b>	1,249,336.33
General Income	1,236,458.07
Membership fees	6,768.55
Donations	3,389.13
Contribution Bühler AG (FFI)	88,953.97
Contribution Vitabiotics	33,155.78
Contribution Mühlenchemie (Smarter Futures)	25,000.00
Contribution Nouryon	25,000.00
Contribution Child-Help organisations	167,412.93
Contribution International Disability Alliance	2,348.10
Contribution Nutrition International	6,284.23
Subsidies PULL project (through Global Alliance for Improved Nutrition)	35,119.61
Subsidies Smarter Futures (through Global Alliance for Improved Nutrition)	349,529.05
Subsidies Ski4All-project (through ASBI)	3,492.00
Subsidies Norad (through RHF)	284,000.00
Subsidies European Commission - Rights, Equality and Citizenship Programme	295,711.00
<b>Deferring income to 2020</b>	<b>-89,706.28</b>
<b>Divers recuperation</b>	<b>11,623.79</b>
<b>Financial Income</b>	<b>1,254.47</b>
<b>RESULT</b>	<b>2,752.16</b>

ALL COSTS (€)	1,246,584.17
General Costs	848,928.76
Housing costs (rent, energy, cleaning)	21,710.94
Office supplies	2,247.31
Publications	5,481.68
Communication costs (website, telephone, postal costs)	6,599.59
Membership of associations	3,096.02
Bookkeeping	4,282.54
Audit	1,815.00
Training staff	217.80
Social and medical secretariat	7,645.30
Insurance	256.92
Consultants - Human Rights	20,990.55
Consultants Food Fortification (Smarter Futures)	171,537.34
Official documents (visa)	1,174.13
Travel costs	130,017.06
Accommodation and subsistence	37,381.06
Conferences - Workshops	70,822.55
Projects: medical material and treatment	37,165.70
Projects: salaries	131,286.54
Projects: training	65,040.88
Projects: advocacy and awareness	42,117.55
Projects: research	5,061.03
Projects: other costs	82,981.27
Salaries	381,979.69

Depreciations and provisions

2,508.12

Taxes and financial costs

13,167.60



2020...



## WHAT'S HAPPENING IN 2020?

By this time of the year, we are all aware of the main topic of 2020: COVID-19 and its impact on our lives. As you can imagine, and as almost all other organisations, IF has had to re-adjust its foreseen workplan for this year, so we have undoubtedly an interesting year ahead of us.

First, the physical events are going to be held online, including the European workshops and the two scheduled events at the European Parliament (EP). The first European workshop is taking place in June through 4 different webinars. We are working hard to make the most out of it for our members!

IF will continue managing and supporting the youth group on their project on sexuality and body awareness. This year, an external researcher will develop an analysis and a report based on the results from the survey launched in 2019. The event at the EP planned for October 2020 will be organised online.

The Working Group on Ageing with SBH consolidates and goes one step forward with regard to its work about the situation of older people with SBH in Europe. IF has hired two researchers that will present a report based on the 650 responses received throughout the survey launched in 2019.

In order to adapt our 2020 workplan to the current situation and especially to the impact of COVID-19 in the SBH community worldwide, we need to know how our members are experiencing this situation so we are asking them and our partners to send us:

- specific information and relevant data about the situation of the COVID-19 related to persons with SBH in your country
- personal testimonies from persons with SBH sharing their experiences during this emergency situation

We would like to use this opportunity to encourage you to contact us and work together! We are all facing the same situation and challenges, no matter which country you are from, your language or culture, we are all in this together. So especially this year, we hope to continue working closely with our members and partners to improve the life of people living with SBH!

