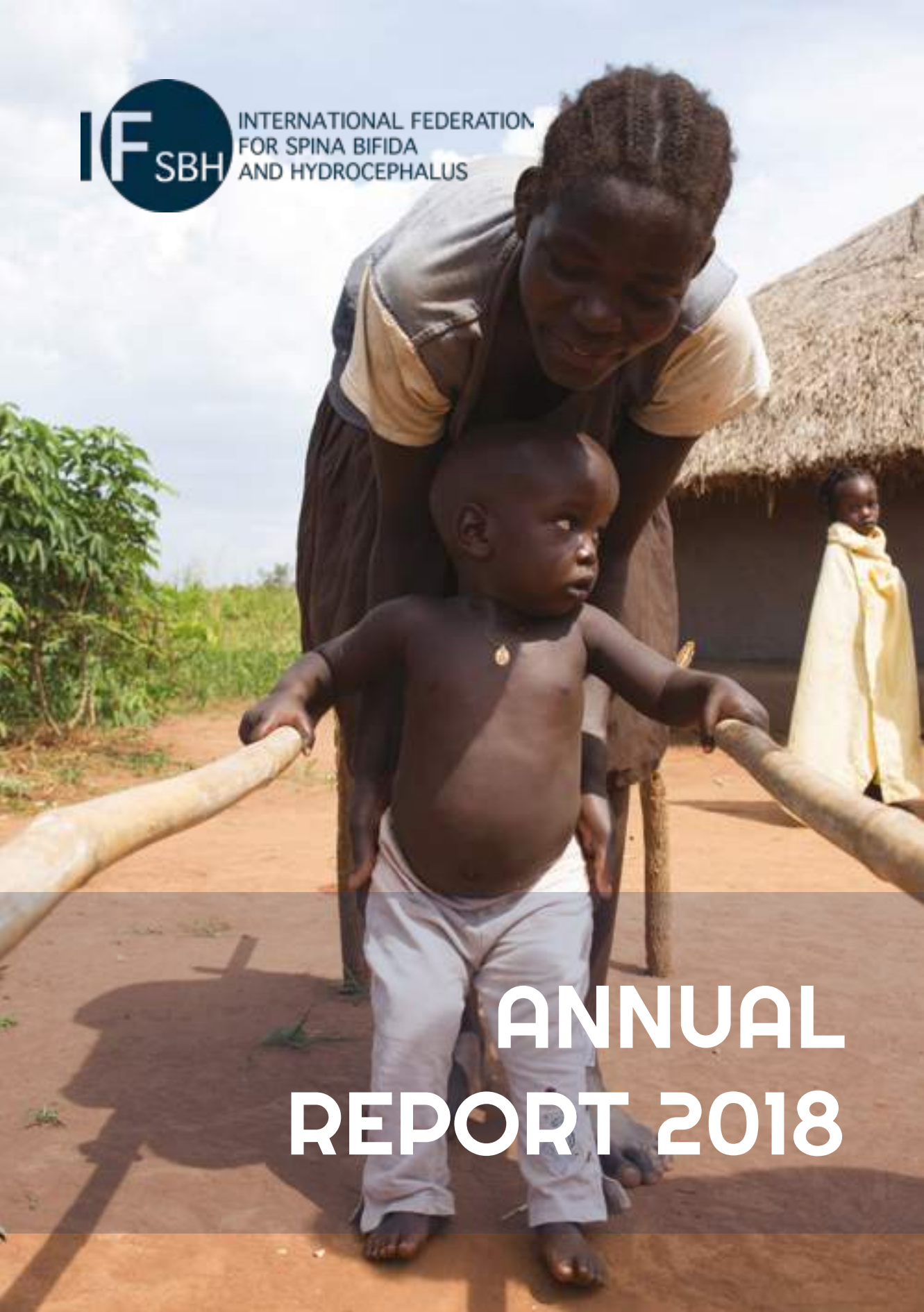




INTERNATIONAL FEDERATION  
FOR SPINA BIFIDA  
AND HYDROCEPHALUS



# ANNUAL REPORT 2018

“Whether you have a disability or not, everyone has their limitations. What I have realised is that I am so much more than my disability. I have spina bifida, but it doesn’t have me”

Testimony of Sarah Hijris for the World Spina Bifida and Hydrocephalus Day #WSBHD18

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**FINANCIAL  
REPORT**



**2019...**

# FOREWORD



Dear friends,

I can hardly believe that I have been President of IF for the past 6 years - where does the time go?

Every year at IF is different with constant changes but one thing that does not change is how busy we are. 2018 has been the first year of our new strategic plan period 2018-2022, which began with so many wonderful activities, challenges and remarkable successes.

The year 2018 saw our International Conference on Spina Bifida and Hydrocephalus happening in India, for the very first time, with families, researchers and medical experts gathering in the beautiful capital of New Delhi. We organised two well-attended European workshops, one in Sofia and one in Madrid, and we celebrated the second anniversary of the IF Global Prevention Initiative, created to raise awareness about ways to prevent neural tube defects and hydrocephalus.

A special mention goes to the 7th World Spina Bifida and Hydrocephalus Day, celebrated as every year on October 25, for which I want to thank everyone who made it a great success by sharing their personal SBH story with us.

A big thank you goes to our members, board of directors, staff and youth group who all contributed to make 2018 a great year for IF.

As I mentioned already, 2018 has only been the first of the five years of our new strategic plan. We're looking forward to the new exciting things that the upcoming years will bring, such as the multidisciplinary care for SBH study that we intend to start in 2019, and the results of the survey on sexuality and body-awareness of people with SBH.

Margo Whiteford  
IF President

# ABOUT IF



## 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 w/ SBH & their families, & reduce incidence of neural tube defects by improving maternal health literacy; by raising awareness, political advocacy, research, community building & human rights education.

## VALUES

**Human rights:** promotion & protection of human rights of people with SBH in accordance with the 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



**Margo Whiteford**  
IF President  
Scotland



**Tom Scott**  
Secretary  
Ireland



**Cato Lie**  
Treasurer  
Norway



**Aziza Mustafa  
Elnaeema**  
Sudan



**Emma Suardiaz**  
Spain



**Elena Zappoli**  
Argentina



**Papatya Alkan**  
Genca  
Turkey



**Nicola Busata**  
Italy



**Frantisek Horn**  
Slovakia

The Board members met twice in person: during the first EU workshop in Sofia (Bulgaria) in May and during the second EU workshop which took place in Madrid (Spain) in November. The General Assembly (GA), held every year, elects the Board biennially.

Last year, the GA took place in conjunction with the workshop in Madrid, where IF members re-elected three Board members: Emma Suardiaz, Cato Lie and Frantisek Horn. We are very happy to count on their continued dedication and expertise at IF!



# the team



**Lieven Bauwens**  
Secretary General



**Janina Arsenjeva**  
European Programme  
Manager



**Renee Jopp**  
Information Officer



**Carmen Clemente**  
Communications  
Coordinator



**Katalijne Van Diest**  
Programme Manager  
International Solidarity



**Anna Verster**  
Senior Adviser on Food  
Fortification



**Martine Austin**  
Programme Manager Global  
Prevention



**Giuseppe Martone**  
Communication Volunteer

We said goodbye to **Ewa Kampelmann**, who worked for IF for more than five years. Ewa started as Communication Officer, next became our Communications Coordinator, and then became IF Deputy Secretary General in October 2016. We're really thankful for all the years she worked with us and for all that she did for IF and the SBH community.

We also said goodbye to our office managers **Nuno Loureiro** and **Ghislaine Gerbier**, who both supported IF in the administrative and financial work, and to our volunteer **Maiken Bekke**, who was part of the communication team.

# global experts panel



**Margo Whiteford**  
Chair



**Amy McPherson,**  
Social Inclusion



**Anne Molloy**  
Causes



**Benjamin Warf**  
Services and  
Care



**David Nolan Morrissey**  
Human Rights



**Richard H. Finnell**  
Genetics

The GEP contributed to the IF response to the call of the Special Rapporteur on the Rights of Persons with Disabilities on the right to health. They were involved with the preparations for the International Conference on Spina Bifida and Hydrocephalus (organised by IF and its member the India Spina Bifida Foundation) which took place in New Delhi (India). Dr. Benjamin Warf, David Morrissey and Dr. Amy McPherson contributed to the programme as speakers.

## **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 Vlieger, anthropology & disability / Wouter De Groote, rehabilitation, psychiatrist / Joanne Maxwell, life skills & transition / Rebecca Opetsi Alitsi, CRPD/SDGs Africa

# european youth group



**Nele Vanhecke**  
Belgium



**Mirela Bukovac**  
Croatia



**Merlin Kizant**  
Estonia



**Elisa Garcia de Ceca**  
Spain



**Ege Anli**  
Turkey



**Adrian Filip**  
Poland

IF European Youth Group is composed of six young people living with spina bifida and/or hydrocephalus and helps us strategize goals and implement activities addressed to youngsters with these conditions.

They come from six different European countries and, beside each being active in the SBH community of their own countries, they collaborate with IF in different ways. They are self-advocates very well prepared and empowered to work towards the needs and rights of young people living with SBH!

# european youth group

*“I have organised some workshop with the young people of the national SBH organisation in Croatia on different topics such as employment. Also, as member of IF Youth Group I participated at the training in Lisbon and I travelled to Brussels to attend the conference on the European Day of Persons with Disabilities. Another great experience was to represent IF and Udruga Aurora at the Eurochild Conference in Opatija (Croatia). There, I participated in the so-called “Human Library”, where people could ask me questions and learn more about my life with spina bifida, like an ‘open book’!”*

Mirela, Croatia



*“The 2018 highlight for me was the creation of our survey on spina bifida and sexuality. I believe this is a topic that is hugely important and one that is not spoken about enough, both within SBH organisations and in society in general. I believe my work with the IF Youth Group will help to change that.*

*Mental health (MH) is also key. Everyone can benefit from talking to a MH professional and that should be no different for people with SBH, who actually face added pressures and struggles in life.”*

Marcus, Ireland - Group on sexuality

## SEXUALITY AND BODY AWARENESS

Towards the end of 2018, a group of young people with SBH had the idea of creating a survey focused on body awareness and sexuality for people living with SBH, a topic that has been never explored enough, and around which a lot of stigma still exists. IF decided to support and coordinate the group, sharing the survey and giving it a lot of visibility through our website, social media channels and presentation at IF EU workshop.



**Who are in the group?:** Iaria Guidotti, Eleonora Giannetti, Elide Bruna, Elisa Garcia de Ceca, Anđela Radovanovic, Ege Anli, Marcus Ward, Fabrizio Calza and Santos Chuwa, nine young people coming from 6 different countries and living with SBH themselves.

**Who is the target?:** especially young people living with spina bifida and hydrocephalus, but also adults.

**In which languages is the survey available?:** by the end of 2018, the survey was already available in English, Spanish and Italian and, at the beginning of 2019, in Flemish, Turkish, Montenegrin and French as well.

**How is it going?:** by the end of 2018, more than 120 people had already participated! Participation in the survey is welcomed until 31 May 2019.

# OUR MEMBERS





## **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)

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 - 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

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

## **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 and 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 (FEBHI)  
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 - Shine Charity  
**Ukraine - Parents Association for Spina Bifida and Hydrocephalus 'Lights of Spirit'**

■ In 2018, IF welcomed **7 new members** from different continents. The new membership structure was approved during the General Assembly celebrated in Madrid and it was published in March 2019.

# PARTNERS



Zakudya omwe zili ndi FolicAc  
zimalandira amayi kupewa  
kubelera mwana wa chilenu  
cha bala pamsana



## **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
- Formerly AkzoNobel, now 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
- Vitabiotics Pregnacare

## IF COLLABORATES ON PROJECTS WITH:

- Atlas Alliance, Norway
- Food Fortification Initiative (FFI)
- Helen Keller International (HKI)
- AkzoNobel, now 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



# NEW STRATEGIC PLAN: 2018-2022



# overview

The disability, human rights and healthcare environments have significantly changed, bringing new challenges and opportunities worldwide. In order to reflect this evolution, and when it approached the end of its previous 3-year strategic plan (2015-2017), IF started to develop a new strategic plan 2018-2022.

Two important steps to this end have been the finalization by the Management Committee last summer and the presentation at the General Assembly in November.

The impact of IF's activity is built on different tiers, starting with the head office in Brussels and moving outward towards our national members, the PUSH! Global Alliance, partners and other organisations that share our values and goals and, ultimately, the general public.

IF's two main priorities for the new strategic period will be to consolidate and strengthen the human rights of people with spina bifida and hydrocephalus, and to facilitate the primary prevention of neural tube defects and hydrocephalus. We aim to do that by raising awareness and through political advocacy, research, community building and human rights education. Our strategy is built upon visibility and capacity.

Visibility means better access to and sharing of quality data regarding SBH research and statistics, more effective and better coordinated communication, and a focus on advocacy, regarding right to health and preventive measure.

As for capacity, IF will continue working with efficient and transparent funding, looking for new grants and private sponsorships, and opening the possibility of funding to individual donors and members.

Furthermore, IF will continue pursuing networking and alliance opportunities with other like-minded initiatives, in particular in the disability and rare diseases sectors, including partner organisations and companies within the new membership framework.





# OUR WORK 2018





# calendar

## JANUARY

- IF celebrated 2nd World Folic Acid Awareness Week
- IF application for 2018-2021 EU grant approved

## FEBRUARY

- IF project visit to Malawi, together with Ryggmargsbrokk- og hydrocephalusforeningen (IF Norwegian member association)

## MARCH

- 4th World Birth Defects Day
- IF joins member organisation ASBI for the kick-off meeting of the project SkiXAll

## APRIL

- IF response to the Special Rapporteur on the Rights of Persons with Disabilities
- IF expresses concerns in response to UNICEF Report: “Every Child ALIVE”

## MAY

- IF EU workshop in Bulgaria

## JUNE

- IF speaks at the 11th Conference of the State Parties to the Convention on the Rights of Persons with Disabilities in New York

## JULY

- Folic Acid Act was passed in Buenos Aires, Argentina
- Afolabi (Festus Fajemilo Foundation, Nigeria) attended, on behalf of IF, the Global Disability Summit in London, UK

- IF and India SB Foundation hold the 28th International Conference “Making the invisible visible” in New Delhi, India
- IF Award 2018 goes to Dr. Agrawal of Surgiwear

## AUGUST

## SEPTEMBER

- IF Bulgarian member at CRPD committee
- IF Global Prevention Initiative launches Women’s Health Wednesday campaign

- IF launches new website
- IF co-hosts “My Right” training in Lisbon (Portugal)
- IFGPI celebrates 2nd anniversary
- 7th World Spina Bifida and Hydrocephalus Day
- IF workshop on organizational capacity assessment for the SBH Association Uganda (SHA-U)
- IF project visit to Uganda, together with its Norwegian member association

## OCTOBER

## NOVEMBER

- IF youth group member Mirela Bukovac at the Eurochild Conference 2018
- Open letter on the EU Work-life balance Directive
- IF statement on World Toilet Day
- IF board member František Horn at “Saving Kidneys” training in Ternopil (Ukraine)
- IF Board members present in webinar on Nutrition and Birth Defects

- IF joins the European Day of Persons with Disabilities 2018

## DECEMBER

# WSBHD 2018

The theme of 2018 World Spina Bifida and Hydrocephalus Day (WSBHD18) was “**Spina Bifida and Hydrocephalus throughout the lifespan**”, with the subtheme “tell us your story”, using #WSBHD18 and #mySBHlife as hashtags.

We aimed for 25 testimonies to be published from October 1 to October 25 but, to our big surprise, the response was so overwhelming that we received more than 60 testimonies!



*“My name is Isaac Ngure Karanu, member of Shak Kenya Thika chapter and a God fearing father of an adult living with spina bifida.*

*My personal doctor had no idea what spina bifida was so I didn't receive enough knowledge of my child's condition. My wife and me learnt about folic acid just 13 years ago when I joined the association. During school years, we had a hard time since he had urinary and fecal incontinence so I had to go to*

*school to change diapers or take clean clothes. Now I am not so protective with him because I noticed that he likes being independent and doing things his own way.”*

**Charles Karanu**



*“For the management of bladder I was helped by a qualified staff. I started to be autonomous around 14/15 years old and, after some time, I learned about my bowel's management. Since my first experience in summer camps, I learned the importance of being clean and taking care of my own body to feel good.*

*I personally think that parents are always over-protective. They always have thousands of fears for the most different reasons. Questions I ask myself are increasing, and they often result in tears and anger, which lead to states of physical discomfort. When I'm not feeling well, I tend to isolate myself. Some people tell me that it's not good for me, but I prefer this way to recover myself”.*

**Benedetta Vania**

## Most of the parents priorities:

- Their feelings and reactions when they received the news about their child's condition
- The importance of CIC and personal experiences
- Peer-to-peer support is key
- Accessibility in public spaces like kindergarten, school, sport venues

## Most of the people with SBH mainly care about:

- Sexuality and relationships, taboos
- Overprotection from their parents
- The importance for them to become and feel independent
- Mental health issues

## Testimonies .....

**42** from people with Spina Bifida and Hydrocephalus and **19** from parents  
**27** videos and **34** texts

Europe **26** Africa **19** North America **5** South/Cental America **9** Asia **2**

## Social media during October 2018 .....

### Twitter

+121,3% profile visits +33 followers  
422 retweets

### Facebook

+ 216 page likes  
2183 page views

## Material produced .....

- 1 social media **toolkit**
- 2 **booklets** with suggested questions
- 2 **banners** for social media
- 3 **articles** on IF website
- 1 **infographic**
- 3 WSBHD **newsletters**

Visit our [Facebook page](#) 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

## ADVOCACY

### IF Global Prevention Initiative (IFGPI)

- **World Folic Acid Awareness Week in January 2018:** with the support of Vitabiotics Pregnacare, IFGPI published posters with key messages on the importance and benefits of folic acid (both fortification and supplementation) and sent 1 call to action and 1 press release to disseminate the awareness campaign.
- **2nd anniversary:** 28th October 2018 marked the 2nd anniversary of the IFGPI. We shared a social media toolkit before the event, encouraging people (particularly subscribers, member organisations, and other relevant NGOs) to celebrate the anniversary with us! There was an increase of followers on the IFGPI Facebook page and we also published a press release to mark the event.
- **“Womens’ Health Wednesday” campaign:** from September 2018, IFGPI publishes a weekly social media poll on Twitter and Facebook to spread awareness about women’s health literacy, especially around topics of neural tube defects and hydrocephalus prevention and healthy pregnancy and preconception. The aim is also to learn what our public thinks about these topics, and what information they have, which will be useful for IF to establish its future IFGPI strategies.





- **Folic Acid leaflet:** IFGPI created and disseminated a leaflet with key information for women, especially in childbearing age, about the benefits of a correct intake of folic acid from before conception. By the end of 2018, the leaflet was translated into X languages.
- **Non-Communicable Diseases (NCD):** engagement with other risk factors has also led to us becoming more actively involved in the prevention of NCD. Advocating at United Nations level, for the inclusion of the critical preconception period in the prevention of this global epidemic in line with global Sustainable Development Goals (SDGs), helping to raise the profile of neural tube defects (NTDs) prevention on a wider global platform.
- **Contributions:** input into European Patients' Forum (EPF) position Statement on Information to Patients on Food and Nutrition. Contribution to International Advocacy Briefing note on Folate Deficiency and Food Fortification.
- Petition to the UN for inclusion of the preconception period in global NCD prevention strategy
- Co-development of an online health professional training module on NTD prevention

## LEARNING

### IF global partner of the Folate Task Team (FTT)

The FTT is a group assembled by Nutrition International in order to advance an action plan for NTDs prevention.

On December 4th, the FTT hosted a webinar titled “Improving child survival at the intersection of nutrition and birth defects” on how improved nutrition can reduce the risk of neural tube defects. Some of the speakers were: Tom Scott (IF Board member; CEO, Spina Bifida Hydrocephalus Ireland), Ruth Nalugya (Chair, Spina Bifida and Hydrocephalus Association of Uganda) and Elena Záppoli (IF Board member; President of Asociación para Espina Bífida e Hidrocefalia Argentina).

## Smarter Futures (SF)

- Conference “Food Fortification: Scalable approaches to prevent micronutrient deficiencies in populations”

On February 15th 2018, the European Commission, International Cooperation and Development, hosted a lunchtime conference at its External Cooperation InfoPoint in Brussels. Presentations were made by: Anna Verster (Senior adviser on food fortification and SF project coordinator) who highlighted the work done by IF in promoting folic acid fortification to reduce the incidence of neural tube defects, Saul Morris from GAIN and Paulus Verschuren from HarvestPlus.

## COMMUNITY BUILDING

- Hosting the Regional Consultative and Capacity Building Workshop on Strengthening Food Fortification Programmes: Monitoring and Surveillance Systems in Johannesburg.

From October 8-10, 2018, the Southern African Development Community (SADC) and the Ministry of Health in South Africa, with support from UNICEF and SF, hosted a workshop that provided SADC Member States with an opportunity to consult and share lessons on the application of the previously learned quality assurance and quality control (QA/QC) approaches with regard to food fortification, within the SADC context.



- **IF and SF involvement in a technical Consultation by the Micronutrient Forum**

With support from the Bill & Melinda Gates Foundation, this consultation aimed to advance the neural tube defects (NTDs) prevention in low- and middle-income countries through improved folate status in women of reproductive age. SF partners the Food Fortification Initiative (FFI) and IF were both involved in the Consultation Review Process and FFI Director Scott Montgomery, FFI Communications Coordinator Sarah Zimmerman and IF Secretary General Lieven Bauwens were acknowledged for the inputs and information they provided.

## OUR MEMBERS' ACHIEVEMENTS ON PREVENTION

- The Spina Bifida and Hydrocephalus Association in Uganda (SHA-U) takes seat in the Ministry of Health Nutrition Technical Working Group to ensure implementation of fortification and supplementation of folic acid.
- Thanks to the advocacy work done by our Argentinian member APEBI, the Folic Acid Act was passed in Buenos Aires, Argentina. This law states that women of childbearing age will be given folic acid for free, both in public and private hospitals in Buenos Aires City.
- On January 10, Association Spina Bifida Maroc organised an awareness raising event as part of the World Folic Acid Awareness Week
- On 8-10 October, ASBAH-SA (South Africa) organised a workshop on food fortification named 'Food fortification programmes: monitoring and surveillance systems'

# RIGHT TO HEALTH

## ADVOCACY

### IF supported youth advocacy song “Never Give Up on Yourself”

3 young adults with SBH from Malawi, Tanzania and Kenya joined hands to write and produce an advocacy song, used in their respective countries to raise awareness. This music group called ‘Courageous Heart Group’ consists of Kennard Pondani (Malawi), Santos Chuwa (Tanzania) and Deborah Nzisa (Kenya). The song was launched for the World SBH Day.

## LEARNING

### 3rd annual training “MY RIGHTS: Independent living, activism and participation for young people with SBH”

The training took place in sunny Lisbon, hosted by our Portuguese member association, ASBIHP. From 5 to 7 October, 11 young people with spina bifida and/or hydrocephalus from Belgium, Croatia, Estonia, Ireland, Portugal, Scotland, Sweden, and Turkey learned, interacted, practiced, improvised and laughed together under attentive guidance of the international team of trainers that included other young persons with disabilities.

All the participants learnt that the Convention on the Rights of People with Disabilities (CRPD) offers a great potential to create a change for young people with SBH and that lack of experience or funding is not an excuse for inaction. If you want it, you should go and get it!



## Project in Malawi with Queen Elisabeth Central Hospital (QECH)

This new research project focuses on **early detection and referral of hydrocephalus**. The aim is to train local health workers as well as the community workers (Health Surveillance Assistants-HSA) to regularly monitor head circumference in newborns and young children. **In 2018 more than 500 health and community workers were trained.**

While the WHO recommends regular monitoring of head circumference, it is not implemented in many countries. This most often results in late identification of hydrocephalus with high risk of secondary disabilities. The final aim of this study is to advocate for the head circumference chart to be added in the Under-5 Health Passport.

**IF fellow and UDPK staff Rebecca Opetsi** was a facilitator at CRPD/SDG trainings in Uganda and Kenya, where she represented our community of people with spina bifida and hydrocephalus.



## Bridge CRPD-SDG training (IF partnership with IDA)

Mr. Kaiba Nadir and Mr. Boudjama Adjaoud from the Algerian SBH Association in Bejaia participated in the first BRIDGE CRPD-SDG training organized for MENA countries from 13-19 December 2018. The program focuses on inclusive and comprehensive understanding of the CRPD as well as generating a CRPD perspective on development in general and the SDGs in particular.

## Project RehApp

IF is contributing to the development of an online app for community fieldworkers: RehApp. This project is coordinated by Enablement, with various other IDDC members/partners. The RehApp is specifically designed for fieldworkers in low-and middle-income countries and aims to enhance their capacity to work with people with disabilities within the community. In 2018 the Spinal Cord Injury-chapter was finalized and it is now available in Google Playstore and Apple Store. We continue with the development of separate spina bifida and hydrocephalus chapters.

# COMMUNITY BUILDING

## European References Network (ERN): a new Working Group Spina Bifida (WG SB)

Through our **European Patients Advocacy Group (ePAG)** member **Ammi Andersson** of our Swedish member RBU, IF continued its advocacy within the **ERN-ITHACA** for a multidisciplinary approach to the treatment and care for people with SBH. Ammi continued to sit on the Board of the ERN-ITHACA and joined the EURORDIS ePAG Steering Group.

As a result, on June 17, the ERN-ITHACA Board approved a proposal for a **WG SB** within the network, which will bring together SB clinicians from various ERNs with SB patient representatives. Along 2018, SB clinicians and representatives of the ERN-ITHACA, eUROGEN ERN and EURORDIS have explored ways of cooperation within the context of the ERNs and have discussed the composition and the work plan for the WG SB for the next 3 years.

Both Ammi and IF Secretary General Lieven Bauwens participated in the 4th ERN Conference, ERNs in Action, on 21-22 November, in Brussels, where they had an informal meeting with ERN-ITHACA Coordinator Prof. Jill Clayton-Smith and Project Manager Michael Smith, to further discuss the activities of the newly established WG SB. On September 13, Ammi attended the ePAG Steering Committee face-to-face meeting in Brussels, on October 9, she took part in the ERN-ITHACA ePAG face-to-face Workshop in Paris, and on November 18, she gave a presentation on the state of affairs with regard to the ERN-ITHACA and the WG SB at IF's European Workshop in Madrid.

## IF and Child-Help International sign a memorandum of understanding (MoU).

In order to make the most of the potential of both organisations, IF and CH signed a MoU to establish and organise clear cooperation and actions between both organisations. The document was signed in October 2018 and we are sure it will result in great projects' outcomes!

## 2 EU workshops in 2018

The **Bulgarian Association of Spina Bifida and Hydrocephalus (SBHB)** was the host of our first EU workshop. They welcomed us in Sofia in May. Main topics:

- Preparations for the European Parliament 2019 elections: the value of the European project and the importance of voting.

- The importance of neurosurgery to survival and optimal health of most people with SBH.
- Understanding of the barriers people with spina bifida experience in managing continence. People with SBH in all countries still face lack of awareness about the importance of continence management, untrained healthcare personnel and widespread stigma about intimate health needs.

The second workshop was hosted by the Madrid Association of Spina Bifida and Hydrocephalus (AMEB) in November in Spain. Main topics:

- Best national practices on continence management, specially cooperation between SBH associations and private sector.
- AMEB approach to person-centered planning of provision of support services to persons with SBH in the community: more personalised and respectful services for persons with disabilities.
- Rights of persons with SBH as passengers of air, rail, ship and coach services. Info about accessibility, assistance, complaint process and compensation.
- Session on “Adulthood and ageing with SBH” that concluded with a discussion around a project for 2019: IF Working Group on Ageing

## 28th International Conference on Spina Bifida and Hydrocephalus

From 10-12 August, IF and its member the Spina Bifida Foundation India hosted in New Delhi (India) the 28th International Conference on Spina Bifida and Hydrocephalus for the first time in Asia.

The IF Award 2018 was given to Dr. G.D. Agrawal, founder of the company Surgiwear in India, which produces the Chhabra shunt for the treatment of Hydrocephalus.



**MAKING THE INVISIBLE VISIBLE**

Building South-East Asian networks to protect the rights of people born with lifelong disabilities

The theme of the conference was “Making the Invisible Visible - Building South-East Asian networks to protect the rights of people born with lifelong disabilities”, where we focused on people with SBH and other birth defects who are deprived of proper medical care and guidance, and their families.

The aim of the conference was to bring together individuals with SBH, their families, their doctors, their advocates, as well as researchers and policy makers, to provide them with up-to-date knowledge, encourage them to cooperate, understand each other’s positions, strengths, weaknesses, roles, and start from there.







## OUR MEMBERS' ACHIEVEMENTS ON RIGHT TO HEALTH

- The Bulgarian association actively participated in their country's review by the CRPD Committee. IF supported them in writing the contribution, and coached them to attend the meetings in Geneva.
- Mr. Kaiba Nadir and Mr. Boudjama Adjaoud from the IF's Algerian member Association des Parents et Malades Spina Bifida Bejaia participated in the first BRIDGE CRPD-SDG training organized for MENA countries.
- Festus Fajemilo Foundation from Nigeria implemented continence trainings both for parents and people with SBH

A photograph of two young girls sitting on a wooden dock by a pond. The girl in the foreground is wearing a pink and white striped long-sleeved shirt and green pants, sitting on the edge of the dock. The girl behind her is wearing a pink and yellow long-sleeved shirt and blue pants, standing. The background shows a pond and a dense forest of tall trees. The text 'COMMS & SOCIAL MEDIA' is overlaid in large red letters on the left side of the image.

# COMMS & SOCIAL MEDIA



Several years ago, IF has decided to dedicate a growing amount of resources to communication activities, as a means to share our values and goals, reaching as many people as possible around the world. Our website and social media channels receive views and interactions everyday, and many people find there a trusted space where they can read about SBH-related news, share their ideas and experiences, and interact with us and other users. Our communication activities are a huge support in giving us more visibility, most importantly, by highlighting everything that we do to improve the quality of life of people living with SBH and increase efforts in the area of prevention.



These are some of the communication activities that we did in 2018:

- For the World Folic Acid Awareness Week, from January 8-14, the IF Global Prevention Initiative created a social media toolkit and a Thunderclap Campaign which achieved 211 supporters and a social reach of 415,960 people.
- For the World Birth Defects Day, we contributed as one of the charter organisations to a Thunderclap Campaign launched by March of Dimes, asking our friends and followers to register with one or more social media account, and agree to post a one-time message on March 3. The campaign achieved 866 supporters in total and a 8,165,151 social reach.

- In September, the IF Global Prevention Initiative launched the “Women’s Health Wednesday”, publishing a poll on social media every week related to improving NTD and hydrocephalus prevention.
- At the beginning of October, IF launched its new website. It is more accessible and better organised compared to the previous one, with a modern design that makes it easy to navigate through different content and resources.
- On World Mental Health Day, October 10, we sent out a special newsletter promoting the importance of mental health and multidisciplinary care.
- Since the beginning of 2018, IF advocated through its website and social media channels for the approval of the Work-Life Balance Directive by the European Union, which was finally approved in March 2019.
- On October 25, we celebrated the 7th World Spina Bifida and Hydrocephalus Day (WSBHD), for which we launched a new successful communication campaign. Being the most important annual event for the SBH community all over the world, we dedicated a special section of this report to the WSBHD.

## SOCIAL MEDIA STATISTICS



**WEBSITE: 76.464 views**



**YOUTUBE: increased from 4.478 in 2017 to 6.132**



**TWITTER: increased from 2.048 to 2.418 followers**



**FACEBOOK: increased likes from 4.894 to 5.652**



**NEWSLETTERS: 12 external, 2 internal, 12 Members’ Voices, 7 press releases**



# FINANCIAL REPORT



# **REPORT OF THE AUDITOR ON THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31-12-2018 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 31-12-2018, prepared under the responsibility of the board of directors of the federation, which show a balance sheet total of € 376.847,04 and a loss for the year of € 13.515,38.**

## **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 31/12/2018 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 26th 2019

Roger De Nul

Auditor

# BALANCE SHEET

Assets (€)	31-Dec-2018	31-Dec-2017
<b>TANGIBLE ASSETS</b>	<b>4.901,41</b>	<b>2.182,87</b>
IT & office supplies	4.250,62	1.532,08
Office furniture	0	0
Cautions	650,79	650,79
<b>AMOUNTS RECEIVABLE</b>	<b>217.517,80</b>	<b>220.906,01</b>
Debtors	5.963,91	8.272,21
Taxes receivable	452,22	0,00
Social charges receivable	1.033,40	0,00
Subsidies to receive	58.858,00	129.904,80
Projects current accounts	30.623,04	0,00
Divers to receive (salary)	754,13	0,00
Child-Help current account	84.110,87	47.220,00
Child Help Intl. current account	35.722,23	35.509,00
<b>BANK &amp; CASH ACCOUNTS</b>	<b>139.589,58</b>	<b>52.026,59</b>
KBC - accounts	45.166,20	50.410,61
KBC - accounts saving	94.415,98	1.615,98
Triodos - accounts	7,40	0,00
<b>TRANSIT ACCOUNTS</b>	<b>14.918,25</b>	<b>61.490,34</b>
Deferred charges	1.390,68	2.727,30
Accrued income	13.527,57	58.763,04
<b>Total assets</b>	<b>376.927,04</b>	<b>336.605,81</b>

Liabilities (€)	31-Dec-2018	31-Dec-2017
<b>RESERVES</b>	196.745,72	210.181,10
Funds of IF	210.181,10	249.997,31
Profit-loss bookyear	-13.435,38	-39.816,21
<b>PROVISIONS</b>	3.088,91	10,000.00
Provision relocation	3.088,91	10,000.00
<b>AMOUNTS PAYABLE</b>	52.379,84	116.424,71
Suppliers	19.823,79	59.309,28
Taxes payable	1.611,00	1.362,00
Salarys' payable	0,00	3.379,19
Provision holiday fee	30.824,18	35.436,30
Projects current accounts	0,00	12.360,94
Divers payable	120,87	4.577,00
Child Help current account	0,00	0,00
<b>TRANSIT ACCOUNTS</b>	124.712,57	0,00
Accrued charges	0,00	0,00
Deferred income	124.712,57	0,00
<b>Total liabilities</b>	<b>376.927,04</b>	<b>336.605,81</b>

# PROFIT AND LOSS

<b>INCOME (€)</b>	<b>1.228.909,52</b>
General Income	1.220.056,74
Membership fees	15.928,00
Donations	3.000,53
Contribution FFI	-52.338,68
Contribution Bühler	83.278,02
Contribution Vitabiotics	22.582,80
Contribution Mühlenchemie (Smarter Futures)	25.000,00
Contribution Child Help Belgium	125.737,53
Contribution Child Help International	34.602,23
Contribution International Disability Alliance	19.210,69
Subsidies: SkixAll project	2.317,50
Subsidies PULL project (through Global Alliance for Improved Nutrition)	101.483,30
Subsidies Smarter Futures (through Global Alliance for Improved Nutrition)	216.179,95
Subsidies Food Inspectors' training (through Global Alliance for Improved Nutrition)	37.984,87
Subsidies Norad (through RHF)	290.800,00
Subsidies MyRight (through RBU)	68.101,56
Subsidies European Commission - Rights, Equality and Citizenship Programme	294.290,00
<b>Diverse recuperation</b>	<b>7.593,63</b>
<b>Financial Income</b>	<b>1.259,15</b>
<b>RESULT</b>	<b>-13.515,38</b>

<b>ALL COSTS (€)</b>	<b>1.242.344,90</b>
General Costs	803.314,28
Housing costs (rent, energy, cleaning)	20.931,67
Office supplies	3.389,92
Publications	1.381,69
Communication costs (website, telephone, postal costs)	9.725,99
Membership of associations	2.254,00
Bookkeeping	6.741,86
Audit	2.783,00
Lawyer	6.911,09
Social and medical secretariat	7.521,87
Insurance	758,70
Consultants - Human Rights training	2.890,00
Consultants - Flour Fortification	110.027,52
IDA Fellowship	1.903,05
Official documents (visa)	944,19
Travel costs	127.119,45
Accommodation and subsistence	42.194,33
Conferences - Workshops	76.556,04
Projects: medical material and treatment	86.929,84
Projects: local salaries	101.347,22
Projects: training	92.757,29
Projects: advocacy and awareness	25.888,58
Projects: research	48.936,86
Projects: other costs	23.420,12
<b>Salary Costs</b>	<b>437.066,48</b>
<b>Depreciations</b>	<b>-4.403,20</b>
<b>Taxes and financial Costs</b>	<b>6.367,344</b>

2019...



## WHAT'S HAPPENING IN 2019?

During the second year of our new strategic plan, IF will continue raising awareness on women's health such as the importance of prevention and preconception through its **“Women's Health Wednesday”** campaign, holding a small event at the European Parliament at the end of the year. In order to put prevention of SBH on top of our agenda, IF's first European workshop of 2019 (to be held Belgrade in May) will focus on that topic, including folic acid fortification.

The new approach to young advocates with SBH has been very successful so far: IF will continue managing and supporting them on their **project on sexuality and body awareness**. A report will be published in summer and IF will organise an event at the end of 2019 to present the results and to establish future steps.

In May 2019, European citizens will elect the new members of the European Parliament, IF will campaign to encourage the SBH community to go voting in these **European elections** by sharing tips, content and information on how to reach national candidates and by raising awareness on the importance of the right to vote.

This year, the **Working Group on Ageing with SBH** consolidates and will start exploring the situation of older people with SBH in Europe.

IF will organise a training of trainers for a selected group of participants from countries in Central and Eastern Europe to promote **understanding of clear intermittent catheterisation (CIC)** for people with neurological disabilities.

Last but not least, there is a special highlight in 2019, our **40th anniversary!** IF will celebrate this special event together with the World Spina Bifida and Hydrocephalus Day and its second European workshop of 2019, in Brussels.

An exciting year is ahead of us, we hope to continue working closely with our members and partners to improve the life of people living with SBH and reduce the incidence of NTDs and hydrocephalus.



INTERNATIONAL FEDERATION  
FOR SPINA-BIFIDA  
AND HYDROCEPHALUS