

# annual report 2016



INTERNATIONAL FEDERATION  
FOR SPINA BIFIDA  
AND HYDROCEPHALUS

Date of publication: May 2017  
Design: Ewa Kampelmann

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Photography: IF, Martha Thooft, Chelsea Bulteel, Sebastiaan Franco  
(Students of KASK Belgian Royal Academy of Arts)

Co-funded by the Rights, Equality and Citizenship programme of the European Union



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# FOREWORD

# F O R E W O R D

Dear Friends,

Our triannual strategy is coming to its end and we are currently developing a new one. I am now in my fourth year as President of IF and I am pleased to report that the work of IF is continuing to expand in most regions of the world. Each year we receive requests for membership from countries whose local organisations are in their infancy and it is exciting to see their enthusiasm for trying to improve the situation for their own group, after meeting our older members at our conferences and workshops.

The PUSH Alliance also continues to grow and the launch of its new website within the last year gives access to the Global Report Cards of the WHO regions which outlines the situation regarding data collection and care available for people affected by SB/H in these regions.


The annual conference in Ghent was well attended and well received although there were some practical problems with regards to the geography of the city and the organisers have taken members' comments on board for organising future events. During the conference we were delighted that HRH Princess Astrid of Belgium was able to be present to help us launch our Global Prevention Initiative

Our continued European funding has allowed further workshops covering a wide range of topics to take place in a variety of European countries with further workshops planned for the coming year in Berlin and Stockholm.

Behind the scenes the IF staff and Board members are constantly working and communicating with other organisations to ensure that the voice of IF is heard around the world. This will hopefully reduce the numbers of babies being born with spina bifida, as a result of primary prevention initiatives and minimise the chance of babies and children developing hydrocephalus, at the same time as ensuring that the quality of life for people already affected by SB/H is improved.

All of this would not be possible without the financial support which we receive from a number of governments and other funders in several countries and I would like to take this opportunity to thank them and let them know that their input makes a definite difference to a very large number of people who experience significant difficulties every day of their lives. It goes without saying, that I would also like to thank my fellow Board members for their input and the hard work of the IF staff which keeps the organisation running smoothly at the same time as constantly expanding and developing new initiatives and ideas.

Last but not least, I would like to thank the IF members for their continued dedication and support to those born with SB/H and their families.



Margo Whiteford  
IF President





ABOUT IF

# A B O U T I F

The International Federation for Spina Bifida and Hydrocephalus (IF) was founded by people with spina bifida and hydrocephalus (SBH) and their families in 1979. Over the years, it has grown from a voluntary association into a professional disabled people's organisation (DPO) with global coverage, democratic structure and transparent and accountable processes.

The majority of IF member organisations are led and governed by adults with SBH or parents of children with SBH. Children and youth are active participants in our members' activities:

## V I S I O N

Our vision of the future is a society that guarantees human rights of children and adults with SBH, and celebrates their contribution in all areas of life; and practices primary prevention of neural tube defects and hydrocephalus.

they are involved in child-led activities, training workshops on independence and holiday camps. In most cases, IF members choose close cooperation with medical and education professionals and researchers, given the importance of these professions to children and adults with SBH for their well-being and development.

IF's fast-growing membership now includes 61 member organisations in Africa, Australia, the Americas, Asia and Europe. Membership of IF is open to all nationally registered organisations that share IF's vision and mission and actively involve people with SBH in their work.

## M I S S I O N

The mission of IF is to improve the quality of life of people with spina bifida and hydrocephalus and their families, and to reduce the incidence of SBH by primary prevention; by raising awareness and through political advocacy, research, community building and human rights education.

## H I S T O R I C A L H I G H L I G H T S

**1979** IF is founded in Stockholm, Sweden (Election 1st IF president Björn Rundström, Sweden)  
**1981** Inaugural meeting in Dublin, Ireland; IF expands to Australia  
**1983** IF expands to the US  
**1991** IF receives Special Consultative Status at the ECOSOC of the UN; IF expands to Asia (Japan)  
**1993** IF starts its projects in developing countries  
**1995** 2nd IF President Pierre Mertens  
**1999** IF starts primary prevention  
**2000** IF moves to office in Brussels; Els Declercq becomes first paid staff member; IF Resolution on Prenatal Diagnosis and the Right to be Different  
**2002** IF expands to Central and South America  
**2004** IF takes part in FFI's Leadership Forum (then Flour Fortification Initiative)  
**2005** IF Policy Statement on Prenatal Diagnosis and the Right to be Different; IF policy statement on prevention of NTDs and mandatory food fortification  
**2006** IF Resolution on active termination of life of newborn children with SBH and the right to live  
**2009** IF position paper on the Groningen Protocol; IF participates in the Smarter Futures project  
**2010/2011** IF prevention campaign "Act against Europe's most common birth defects"  
**2011** Lieven Bauwens, IF secretary general, becomes member of FFI's Executive Management  
**2012** IF position paper on healthy ageing; October 25 is the first World Spina Bifida and Hydrocephalus Day  
**2013** 3rd IF President Margo Whiteford  
IF becomes a member of EURORDIS  
IF joins the Fundamental Rights Platform of FRA; Active & healthy EU citizens – survey report; October 25: Launch of PUSH  
Introduction of SHIP passports  
**2015** China joins IF; World Birth Defects Day  
**2016** IF starts cooperation with SBH clinicians in the EU to join European Reference Network; PUSH! Global Alliance report cards; IF Global Prevention Initiative; IF joins the International Disability Alliance; IF statement on multidisciplinary care; IF staff consists of 9 paid staff members  
IF membership has grown to 61 members



# OUR BOARD



IF is an International NGO according to Belgian law. The General Meeting held every year elects the Executive Board bi-annually. External auditors control and approve the financial statements. The IF Board meets twice a year. These meetings are held in different countries and are connected whenever possible to the local meetings and study visits.

In 2016 we said thank you and goodbye to: Thelma Cloake (Ireland), Nurdan Emine Anli (Turkey), Santosh Karmarkar (India), and Lumbwe Chiwele (Zambia).

IF current Board Members are:

Mrs. [Margo Whiteford](#), IF President, Scotland  
Mrs. [Papatya Alkan Genca](#), Turkey

Mr. [Nicola Busata](#), Italy  
Dr. [Aziza Mustafa Elnaeema](#), Sudan  
Dr. [František Horn](#), Slovakia  
Mr. [Cato Lie](#), Norway  
Mr. [Tom Scott](#), Ireland  
Mrs. [Emma Suardiaz](#), Spain  
Mrs. [Elena Zappoli](#), Argentina



# OUR TEAM IN 2016



LIEVEN  
BAUWENS

Secretary General



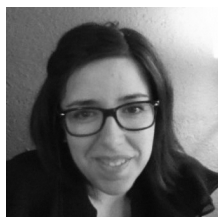
JACKIE  
BLAND

Development  
Director (until June  
2016)



EWA  
KAMPELMANN

Deputy Secretary  
General (as of  
October 2016)



MARTA  
ANGUERA

Communications  
Officer (until  
August 2016)



JANINA  
ARSENJEVA

Europe  
Programme  
Manager



MARTINE  
AUSTIN

Programme  
Manager Global  
Prevention



RENEE  
JOPP

Information  
Officer



JANA  
MORAVCOVA

Advocacy Officer



VIVIANA  
SPECIOSO

Erasmus +  
Volunteer  
(until July 2016)



KATALIJNE  
VAN DIEST

Programme  
Manager  
International  
Solidarity



ANNA  
VERSTER

Senior Advisor  
Smarter Futures



MARGO  
VANDEBROUCKE

Administrator



OUR MEMBERS

# O U R M E M B E R S

**Algeria** Association des Parents et Malades Spina Bifida Bejaia - **Argentina** Asociación Para la Espina Bífida e Hidrocefalia (APEBI) - **Australia** Spina Bifida Association Queensland; Northcott Spina Bifida Group - **Austria** Spina Bifida und Hydrocephalus Österreich (SB&HÖ) - **Belgium** Association Spina Bifida Belge Francophone (ASBBF); Vlaamse Vereniging voor Spina Bifida en Hydrocephalus vzw (VSH) - **Bulgaria** Spina Bifida Hydrocephalus Bulgaria - **China** China Association of Persons with physical Disabilities (CAPPD) - **Colombia** Fundación Mónica Uribe Por Amor - **Croatia** Udruga osoba i roditelja djece sa spinom bifidom “Aurora” - **Denmark** Rygmarvsbrokforeningen af 1988 - **Estonia** The Estonian MMC and HC Society - **Finland** Suomen CP-liitto ry - **France** Fédération Française des Associations du Spina Bifida (FFASB) - **Germany** Arbeitsgemeinschaft Spina Bifida und Hydrocephalus e.V. Bundesverband (ASBH) - **Greece** Hellenic Association for Spina Bifida and Hydrocephalus - **Guatemala** Asociación Guatemalteca de Espina Bífida (AGEB) - **Honduras** Fundación Amado Josue - **Hungary** MEOSZ - **India** Spina Bifida Foundation - **Ireland** Spina Bifida Hydrocephalus Ireland (SBHI) - **Italy** ASBI Associazione Spina Bifida Italia - **Japan** Japan Council for Spina Bifida and Hydrocephalus; Spina Bifida Association of Japan - **Kenya** Spina Bifida and Hydrocephalus Association Kenya (SHAK) - **Latvia** Latvijas spina bifida un hidrocefālijas biedrība (LSBH) - **Lithuania** Spina Bifida ir Hidrocefalija asociacija - **Luxembourg** Association pour le Spina Bifida a.s.b.l. - **Malaysia** Spina Bifida Association Malaysia (SIBIAM) - **Mexico** Asociación Mexicana de Espina Bífida A.C. (AMEB) - **Mongolia** Mongolian Spina Bifida Foundation “Maral Angel” - **Morocco** Association Spina Bifida et Handicaps Associés au Maroc - **The Netherlands** BOSK Work Group Spina Bifida & Hydrocephalus - **Nigeria** Festus Fajemilo Foundation - **Norway** Ryggmargsbrokk- og hydrocephalusforeningen - **Peru** Asociación de Espina Bífida e Hidrocefalia del Perú (ASESBIH) - **Poland** Fundacja “Spina” - **Portugal** Associação e Spina Bífida e Hidrocefalia de Portugal (ASBIHP) - **Romania** Asociatia Romana de Spina Bífida e Hidrocefalie (ARSBH) - **Russia** Association of Spina Bifida and Hydrocephalus of St. Petersburg - **Scotland** Scottish Spina Bifida Association (SSBA) - **Serbia** Spina Bifida and Hydrocephalus association of Serbia **Slovakia** Slovenská spoločnosť pre Spina Bifida a/ alebo Hydrocephalus, o. z. - **South Africa** Association for Spina Bifida and Hydrocephalus - South Africa (ASBAH-SA) - **Spain** Federación Española de Asociaciones de Espina Bífida e Hidrocefalia (FEBHI); Associació Catalana d’Espina Bífida i Hidrocefalia (ACAEBH); Asociación Madrileña de Espina Bífida e Hidrocefalia (AMEB) Asociación Murciana de padres con hijos de Espina Bífida e Hidrocefalia (AMUPHEB) - **Sudan** Spina Bifida Federal Association - **Sweden** RBU; Spin-Off - **Switzerland** Schweizerische Vereinigung zugunsten von Personen mit Spina Bifida und Hydrocephalus (SBH) - **Tanzania** Association for Spina Bifida and Hydrocephalus Tanzania (ASBAHT) - **Turkey** Türkiye Spina Bifida Derneni - **Uganda** Central Uganda Spina Bifida and Hydrocephalus Network - **UK** SHINE - **USA** Spina Bifida Association of America (SBAA); Hydrocephalus Association; Pediatric Hydrocephalus Foundation

\* joined in 2016



# OUR YOUTH GROUP



EGE ANLI

Turkey



MIRELA  
BUKOVAC

Croatia



ADRIAN  
FILIP

Poland

Youth empowerment became one of the main priorities of the IF strategic plan 2015-2017.

The IF Youth Group was therefore set up in order to:

- make young people experienced self-advocates on Spina Bifida and Hydrocephalus (SB/H) issues, and
- develop IF's work on issues that are very important to young people with SB/H

“The IF Youth Group was created so that we, young people with SB/H are able to discuss and address our problems ourselves. Young people with the SB/H condition, know what challenges are experienced by their peers; they can exchange ideas and experiences on how to support young people to overcome these challenges. We would like to make youth with SB/H more visible on the level of international disability rights work and to suggest possible solutions to challenges facing youth with SB/H in different countries.”



ELISA GARCIA  
DE CECA

Spain



MERLIN  
KIZANT

Estonia



NELE  
VANHECKE

Belgium

Previous Youth Group members in 2016



DOMINIK  
DRDUL

Slovakia



ROWAN  
FORD

UK

[www.facebook.com/ifyouthcommunity](http://www.facebook.com/ifyouthcommunity)



“In 2016 we had meeting in Brussels in July and we attended a UNCRPD training. We also learned many things on group dynamics and we started to work more effectively. We set goals more realistically and specifically. We also realised that the **FB group** was our best asset to reach a wider community of young people with SB/H. Consequently, we decided to focus on the FB page and that it should be more active. We started to share work between us more fairly. Our motivation rose.

The CRPD training was very helpful as we learned about the UNCRPD: the rights we have, and the obligations that the member states to the Convention have. It was curious that for us, young people with disabilities, the UNCRPD was something that we did not quite

know about, which can be the case, unfortunately, for many young people with SBH.

Our second meeting took place in Ghent where the YG had many tasks. We were the ones responsible for the moderation of the event on transition and care, and ask the experts sessions. In the first event about transition and care we had the opportunity to talk first of all about self-awareness from our own personal experiences. We learned from the experts about many topics related to transition: we discussed sexuality in the context of disability in relationships, parenthood and SB, ageing with a chronic disability, and, finally inclusive education.

Throughout the session we kept a live report on social media to keep informing our followers on

FB about what we were learning. We also did a presentation in the EU Workshop about the year of YG work where we outlined what went well, what did not, what were our future plans, and what support we needed from IF. This exercise of self-criticism was a very practical and useful exercise. We feel that we began to form that bond of friendship and the ability to work well as part of a team and starting to form professional relationships not just with each other but with people that we met.

Finally, we were given the opportunity of recording a video with professionals on the subject. The video was about self-advocacy and it was all made by the YG. Purpose of the video was to help encourage youth for more active participation.”



# OUR GLOBAL EXPERTS



MARGO  
WHITEFORD

Chair



AMY  
MCPHERSON

Social Inclusion



ANNE  
MOLLOY

Causes



BENJAMIN  
WARF

Services and Care



DAVID  
NOLAN  
MORRISSEY

Human Rights



RICHARD H.  
FINNELL

Genetics

[www.ifglobal.org/en/who-we-are/experts](http://www.ifglobal.org/en/who-we-are/experts)

The members of the Global Experts Panel advise and represent IF on a broad range of matters in their areas of expertise, including, but not restricted to, newly published research, contributions to press releases or position papers, the preparations of IF's annual

International Conferences and help develop the Global Experts Network. Members of the Global Experts Panel are considered the public spokespersons for IF on the topic of their specialty. To perform its tasks, the Panel consult the members of IF's Global Experts

Network, and receive support from the IF secretariat. The position is considered self-funded. In 2016 the GEP was consulted on the [IF Statement on Multidisciplinary Care for the treatment of children and adults born with Spina Bifida and Hydrocephalus](#).

## Composition of the Global Experts Network:

- Ronald Afdra, FFI Africa Network Coordinator
- Femke Bannink, Senior Advisor/ Researcher
- Richard Bransford, general surgeon, MD, FACS
- Myleen Christiaens, consultant on Spina Bifida
- Filippo Ciantia, tropical medicine, Expo 2015
- Kordelia Fischer-Borchert, consultant, community-based rehabilitation
- Philippe Gillis, consultant paediatrics and tropical medicine
- Helen Healy, consultant life skills and transition
- Marisol Hernandez, IF liaison in Buenos Aires
- Bo Hjelt, consultant fundraising and general management
- Liu Jiarong, IF liaison in Beijing
- Joe Mulinare, prevention expert, former CDC
- Koen Sevenants, senior advisor, Development Cooperation Asia
- Carla Verpoorten, medical consultant, neuro-paediatrician
- Patrick De Vlieger, anthropology and disability
- Wouter De Groote, rehabilitation





PARTNERSHIPS



# PARTNERSHIPS

The International Federation for Spina Bifida and Hydrocephalus is constantly enlarging its international network through projects and partnerships.

At IF we build on the experience of our member organisations as we listen to the needs of organisations at grassroots level to channel these to policy and decision makers at international level. Many of the issues we are working on are also priorities for other international organisations, and we believe in positive cooperation to have an even greater impact on international policies and programmes.

The International Federation for Spina Bifida and Hydrocephalus holds Special Consultative Status at the Economic and Social Council of the United Nations and Participatory Status at the Council of Europe. Since 2011 Lieven Bauwens, IF Secretary General represents IF in the Executive Management Team of FFI. IF is a full member of the IDDC, IDA, EDF, EPF, RDI and EURORDIS. In 2014 IF initiated PUSH! Global Alliance - a platform for organisations to advance the greatest benefit to those affected by spina bifida and hydrocephalus.

Besides our member organisations, we regularly link up to other networks to exchange best practice, and also grow our network, on which we rely for our events, projects and advocacy work.

IF is a 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)
- International Disability Alliance (IDA)

IF has an official 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 Union Agency for Fundamental Rights (FRA)

- WHO Partnership for Maternal, Newborn & Child Health (PMNCH)

IF collaborates on projects with:

- Atlas Alliance, Norway
- Liliane Fonds
- Food Fortification Initiative (FFI)
- Helen Keller International (HKI)
- Ministry of Foreign Affairs of the Netherlands
- Akzo Nobel
- Boston Children's Hospital
- March of Dimes
- University of Toronto, Sunnybrook Health Sciences Centre
- CURE International and CURE Hydrocephalus
- CDC's National Center on Birth Defects and Developmental Disabilities
- University of Ghent

IF's partners in developing countries:

- CURE Children's Hospital Uganda
- Organised Useful Rehabilitation Services Uganda (OURS)
- Katalemwa Cheshire Homes Uganda
- AVSI Gulu Uganda
- Spina Bifida and Hydrocephalus Awareness Network, Uganda (SHYNEA)
- Spina Bifida and Hydrocephalus Association Uganda (SHA-U)
- BethanyKids at Kijabe Hospital Kenya (BKKH)
- Beit CURE Hospital Zambia
- Queen Elizabeth Central Hospital, Malawi
- Parents Association for Spina Bifida and Hydrocephalus Ltd, Malawi (PASHL)
- Zambian Association for Hydrocephalus and Spina Bifida (ZAHSB)

IF gets a financial contribution from:

- European Union (EU)
- Bühler
- Vitabiotics Pregnacare
- The Global Alliance for Improved Nutrition (GAIN)
- Child - Help International
- MyRight
- NORAD, Norway through the Norwegian Association for Spina Bifida and Hydrocephalus

# STRATEGIC OBJECTIVES 2015-2017



## P R I M A R Y   P R E V E N T I O N

Prevention of neural tube defects and hydrocephalus is improved globally.

National decision-makers better understand cost-effectiveness of primary prevention and take measures to increase public awareness about it.

National folic acid fortification strategies are adopted in cooperation with the public and private stakeholders.

IF gains more insight in the prevention of acquired hydrocephalus.

## R I G H T   T O   H E A L T H

Children and adults with spina bifida and hydrocephalus enjoy timely access to appropriate and affordable healthcare and rehabilitation of high quality without discrimination or prejudice.

Information about the rights of children and adults with SBH in healthcare is widely available for people with SBH and their families, medical and para-medical professionals and political decision-makers in appropriate and accessible formats.

## C O M M U N I T Y   B U I L D I N G

National associations of SBH feel the ownership of IF and feel empowered to advocate for full respect of human rights of people with SBH, and to provide their members with high-quality support.

More children and adults with SBH feel part of a global community that also includes researchers, healthcare professionals and everyone with an interest in SBH.



JANUARY

IF participated in the Public Hearing of EP on CRPD



FEBRUARY

IF reacted to the EC proposal for the Accessibility Act

We celebrated Rare Diseases Day



MARCH

PUSH! Global Alliance launched its new website and the Global Report Cards on the occasion of the World Birth Defects Day

IF participated in GAIN Workshop in Tajikistan

IF responded to the European Disability Strategy Review

IF participated in the IDA Board Meeting (for the first time)



APRIL

IF was represented at EASPD Annual Conference

PUSH! Global Alliance launched second round of Report Cards

IF attended the IDDC General Assembly

IF representatives attended the official opening of the BethanyKids Children's Centre at Kijabe Hospital, Kenya



MAY

IF attended the Public Hearing on Concluding Observations of UN CRPD Committee

Mission in Ethiopia with Child-Help and CURE

We organised the training workshop on Quality Assurance and Quality Control in Uganda

IF launched Good Practices website



JUNE

European Conference on Rare Diseases & Orphan Products on advocacy

IF's European Workshop in Budapest

IF at the 9th session of the Conference of States Parties to the CRPD

Work visit to Bolivia in cooperation with Child-Help

FORTIMAS training of leaders for fortification monitoring & surveillance took place in Mozambique

"Who am I" workshop for youth in Tanzania





J U L Y

Young people with SB from Slovakia raised awareness about children with disabilities at Eurochild conference in Brussels and Disability Intergroup of the European Parliament in Strasbourg



A U G U S T

IF Statement on Multi-disciplinary Care was launched



S E P T E M B E R

We launched a Joint Statement: calling on MEPs to cast a positive vote for the report "Creating labour market conditions favourable for family-work balance"



O C T O B E R

Elisa (YG member) took part in UN Human Rights Council Social Forum in Geneva

Celebrations of the World Spina Bifida and Hydrocephalus Day worldwide

Launch of the Global Prevention Initiative at IF's International Conference in Ghent

IF Awards were given to Myleen Christiaens and Catalina Devandas

Africa Network event and Maize Fortification Strategy Meeting took place in Tanzania



N O V E M B E R

FORTIMAS published in Portuguese

IF spoke at NGO Committee for Rare Diseases in New York

IF attended a conference on the proposal for a European Accessibility Act

Visit to our partners in Uganda

IF publishes a response to the consultation on provision of support to persons with disabilities



D E C E M B E R

Celebration of the 1st European Disability and Development Week as well as the World Day of People with Disabilities

Celebration of Africa's effort in flour fortification



**It's here!**

**Spina Bifida and Hydrocephalus  
Awareness Week 2016**

#GoYellow • [www.shinecharity.org.uk](http://www.shinecharity.org.uk)

**L'AMORE  
PER TE E PER CHI AMI  
INIZIA DALLA  
PREVENZIONE**

OTTOBRE È IL MESE DELLA SPINA BIFIDA

**A.S.B.I.**

[WWW.SPINABIFIDAITALIA.IT](http://WWW.SPINABIFIDAITALIA.IT)

Comunicazione promossa dalla Corte di Laurea di Bari, Bari, Bari, Bari








# 25 OCTOBER WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY

Spina Bifida and Hydrocephalus Awareness Week 2016  
incorporating  
World Spina Bifida and Hydrocephalus Day  
25<sup>th</sup> October 2016

**#WhatsYourStory?**

Each day from 24<sup>th</sup>-30<sup>th</sup> October SBHI will be releasing a member story online - we need you to respond with your own experience to help raise awareness of Spina Bifida and/or Hydrocephalus



**Story 1**  
**Alyssa Reeves**

[www.sbhi.ie/aw2016](http://www.sbhi.ie/aw2016)





# PRIMARY PREVENTION



## FOOD RICH IN FOLIC ACID

Folic acid may be found in varieties of foods that include:

1. Boiled eggs
2. Cabbages
3. Mushrooms
4. Avocados
5. Fresh maize
6. Fresh vegetables
7. Fresh mangoes
8. Beans
9. Soya beans
10. Green peas
11. Cassava and Liver
12. Pumpkin leaves
13. Fresh bananas
14. Groundnuts
15. Oranges



STRONGERTOGETHER

STRONGERTOGETHER



# A D V O C A C Y G l o b a l P r e v e n t i o n I n i t i a t i v e

On the occasion of the World Spina Bifida and Hydrocephalus Day in October 2016, IF, supported by HRH Princess Astrid of Belgium, has officially launched a global campaign on primary prevention of NTDs and Hydrocephalus.

Its goal is to unite all relevant organisations, NGOs, Governments, policy makers, health services, health professionals and individuals around the world to maximize the risk reduction of NTDs and hydrocephalus.

NTDs affect around 500,000 live births every year. Spina bifida, the most common NTD, is the most severe birth defect compatible with life, and anencephaly is almost always fatal. Yet the majority of these birth defects is easy to prevent! In 1991, a landmark study by the Medical Research Council discovered that folic acid (vitamin B9) could reduce the risk of NTDs significantly, by up to 72%. However 25 years on, we are still only managing to prevent around 15% of the cases that we could!

The GPI is the first initiative of its kind, that aims to tackle the primary prevention of Neural Tube Defects and Hydrocephalus as a united global community.

By joining forces and addressing the issue together, we can support sustainable action and awareness on a global level, to maximise the prevention of these disabilities. We will help to support all IF members, and WHO member states in developing regional and national plans for the implementation of effective prevention interventions, including the development and delivery of effective prevention initiatives and food fortification strategies, in line with the aims of the WHO.



## K E Y R E S U L T S

300 participants at the GPI launch

379 official GPI supporters

117 followers of the IF Global Prevention Initiative facebook page

1 new publication on Folic Acid

8 new resource pages on prevention were added to our website

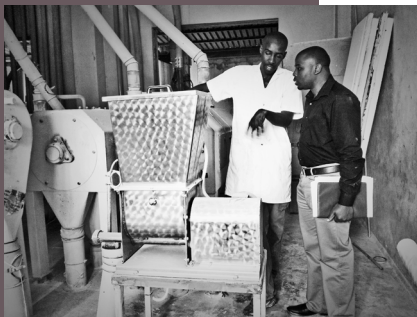
1 article published on prevention

First Folic Acid Awareness Week organised in January 2017

[www.ifglobal.org/en/what-we-do/global-prevention](http://www.ifglobal.org/en/what-we-do/global-prevention)

# LEARNING & EXCHANGE

## Smarter Futures project



Smarter Futures is a project which provides technical support and training for flour millers, government food control staff, and other stakeholders in Africa with regard to fortification of wheat and maize flour with vitamins and minerals. Adding vitamins and minerals to flour is economically viable and cost effective. Improving the nutritional value of people's diets through fortification of flour will improve people's health and well-being and lead to smarter futures.

The partners involved are: the Food Fortification Initiative, AkzoNobel, Helen Keller International, and the International Federation for Spina Bifida and Hydrocephalus (IF), with the financial support of the Ministry of Foreign Affairs of the Netherlands.

The key groups to benefit are women of childbearing age, adolescents (especially girls) and young children. Additional nutrients, especially iron and folic acid, make these group in particular smarter, stronger, and healthier.

At the occasion of the Smarter Futures Steering Group meeting held 17 & 18 December 2015 in the Ministry of Foreign Affairs, The Hague, the Netherlands, the Ministry and Smarter Futures jointly hosted a lunch seminar entitled "Flour Power, Fortification for a Smarter Future".

In November 2016, Smarter Futures published a new language version of its FORTIMAS tool- in Portuguese. Globally 86 countries have legislation to mandate fortification of at least one industrially milled cereal grain. However, many countries have struggled with how to assess the impact of this public health intervention over time.

Smarter Futures held several events in 2016: Africa Network Event and Maize Fortification Strategy Meeting in Dar es Salaam, FORTIMAS training of leaders for fortification monitoring and surveillance in Mozambique, and Training workshop on Quality Assurance and Quality Control in Kampala.





Maize Fortification Strategy meeting for Africa, where participants coming from 14 countries met to discuss challenges and opportunities of mandatory maize fortification.

By the end of 2014, 24 countries in Africa had mandatory legislation for wheat flour fortification to provide essential vitamins and minerals to their populations, while in another 3 countries millers did so voluntarily. In 2016, 27 countries had mandatory legislation for wheat flour fortification and millers in another 5 do so voluntarily. In addition to this increase we also see that 9 countries have mandatory legislation also for maize flour, while in 2 other countries millers do so voluntarily.



RIGHT TO HEALTH





## ADVOCACY

### Multidisciplinary care

IF wrote a response to the consultation of the Special Rapporteur on the rights of persons with disabilities. We pointed out the lack of data and expertise with regard to Spina Bifida and Hydrocephalus (SBH) and the need for a multidisciplinary approach throughout the life cycle for people living with these conditions.

In October 2016, we organised a workshop for SBH clinicians on multidisciplinary care, foetal surgery and European Reference Networks.

## IF calls for equal treatment in Europe

We were requested to answer the European Commission public consultation on the mid-term review of the European Disability Strategy 2010-2020. After a thorough consultation with our members on the challenges they meet in the areas covered by the European Disability Strategy and how the EU should address them, **IF expresses its concerns and made recommendations** to ensure the full and equal participation of persons with spina bifida and hydrocephalus (SBH) in society.

To assist our members in their advocacy work, we published our **“Statement on Multidisciplinary Care for the treatment of children and adults born with Spina Bifida and Hydrocephalus”**. It is essential that all specialists and services cooperate and coordinate to make sure that children and adults with SBH achieve the highest attainable standard of health. In addition, receiving multidisciplinary care will reduce the need for multiple appointments, often at different locations. Services need to be age-appropriate and should include measures to ensure a proper transition from paediatric to adult multidisciplinary care for SBH.

IF attended the hearing on the Concluding observations to the EU of the UN CRPD Committee.

We were pleased to see that the European Commission answered to the recommendation in Article 9 of the Concluding Observations of the CRPD on Accessibility and published the long awaited European Accessibility Act.

## KEY RESULTS

Participation at public hearings and being a watchdog of the work done by the European institutions and the UN

Contribution to the reports and consultations by other stakeholders

256 respondents to CBHC and 368 to SBH surveys

IF Statement on Multidisciplinary Care for the treatment of children and adults born with Spina Bifida and Hydrocephalus

1 training on EU Cross-border Healthcare Directive

1 webinar on UNCRPD

12 CRPD wallpapers

1 workshop on transition in Africa

2 representatives at the EURORDIS European Patient Advocacy Group for European Reference Networks

2 surveys resulting in 2 reports: “Right to health: reality of persons with SBH”, and “Impact of cross-border healthcare on persons with disabilities and chronic conditions”

## LEARNING & EXCHANGE

### Our trainings

In June 2016, during the European workshop in Budapest, our members had an opportunity to get a **training** on the Cross-border Healthcare Directive by a representative of the European Patients' Forum.

In July, we organised a **webinar** on the UN Convention on the Rights of People with Disabilities: "No more charity: human rights approach to disability" where we tackled the most relevant articles on the convention for people with SBH: right to legal capacity, right to health, and right to education.

In June 2016 IF organised a **youth workshop** on transition in Tanzania. Topics covered were varying from sexuality, discrimination, social action, relationships, inclusion, leadership, and entrepreneurship.



## PROCESSES European Reference Networks

In May 2016 EURORDIS developed a European Patient Advocacy Group (ePAG) for each European Reference Network (ERN) disease grouping to ensure that the needs of all people living with a rare disease are considered and included in the ERN development process.

For this reason, Ammi Sundqvist Andersson from the Swedish Association for Children and Young People with Disabilities and Luís Quaresma from the Spina Bifida and Hydrocephalus Association of Portugal, members of the International Federation for Spina Bifida and Hydrocephalus, have been elected Patient Representative of the Rare Malformations, Developmental Anomalies and Intellectual Disabilities ePAG.

On December 15, 2016, the European Reference Network on Rare Congenital Malformations and Rare Intellectual Disability (ITHACA) became official (together with 22 other ERNs), which made Ammi an official SBH representative on the ITHACA Board on behalf of IF.



## KNOWLEDGE research on access to healthcare

Citizens with disabilities continue experiencing inequalities and barriers in enjoying their right to health both home and abroad. This was the key worrying finding of the research IF undertook in 2016: “Right to health: reality of persons with Spina Bifida and Hydrocephalus”, and “Impact of cross-border healthcare on persons with disabilities and chronic conditions”. Human rights of persons with disabilities and

chronic conditions are routinely violated as they struggle to access appropriate and affordable disability-specific as well as general healthcare in their community. Lack of multidisciplinary care for people with complex disabilities, such as SBH, limited coverage of mobility devices and continence aids, as well as waiting times have been named as the most serious barriers experienced by surveyed Europeans.



# COMMUNITY BUILDING





ADVOCACY & COMMUNICATION  
PUSH! Alliance report cards  
www.push.org

PUSH! Global Alliance (People United for Spina Bifida and Hydrocephalus) is the global voice for organizations working worldwide to better the lives of people living with spina bifida and hydrocephalus. The goals are to advance surveillance and prevention efforts, to improve quality of care, and to eliminate disparities in access to care, through research, communications and capacity building.

On 3 March 2016, PUSH! called on the public and policy makers to take action to prevent SBH in observance of World Birth Defects Day.

On World Birth Defects Day the PUSH! Global Alliance launched its website and Global Report Cards providing country-level information on hydrocephalus and spina bifida

Good Practices  
www.ifgoodpractices.org

In June 2016, we launched a new website aimed at showcasing best practices developed by IF member. The objective of Good Practices was to: encourage IF members to exchange good practices that help other members improve their work, provide a role model to inspire

prevention efforts, access to care, quality of life, and availability of prevalence and mortality data.

In April 2016, PUSH! launched its second round of Global Report Cards from Eastern Mediterranean Region (EMRO) and Western Pacific Region (WPRO), providing country-level information on hydrocephalus and spina bifida prevention efforts, access to care, quality of life, and availability of prevalence and mortality data.

PUSH! would like to acknowledge the Center for Spina Bifida Prevention at the Rollins School of Public Health of Emory University for its assistance in making the Global Report Cards for Spina Bifida and Hydrocephalus Prevention and Care a reality.

other members and promote best practice and expertise, and to commit to the ongoing goal for further IF members cooperation. One of the good practices-Estonia, resulted in an advocacy workshop on Rehabilitation and active lifestyle that took place in September 2016.

KEY RESULTS

1 General meeting

All 6 WHO regions were examined and country-level scorecards for spina bifida surveillance, prevention and care were produced

6 members presented their good practices online

2 workshops for IF European members (for over 90 participants)

1 training for youth on CRPD for 9 participants

Over 300 participants from 37 countries attended our International Conference

Expansion of IF members: 61

1 new member of the LATAM network

23 clinicians participated in ERN SBH meeting

14 SBH clinicians from 9 European countries took part in ERN workshop

1 new IF Youth FB page

12 monthly Members Voice and general newsletters

## IMPROVING KNOWLEDGE CRPD advocacy training

In November 2016 we organised the training course for young people with disabilities in Ireland. The objective of the course - to empower youth with disabilities to have their voice heard - was implemented in sessions on human rights of people with disabilities, Irish anti-discrimination legislation, youth activism and local-level advocacy. One of the results was an advocacy video prepared by participants.



## Our LATAM network grows

A new group of parents created a Bolivian network for Spina Bifida and Hydrocephalus with the support and close collaboration of Child - Help and APEBI (our Argentinian member). At the working visit to Bolivia parents and professionals mapped the many barriers parents and children face hindering them to have access to care for Spina Bifida and Hydrocephalus.



## LEARNING & EXCHANGE Trainings for EU members

In 2016 we organised two well-attended workshops for our members coming from the EU. The first one took place in Budapest and the second one in Ghent.

Our members had the opportunity to get an update of IF's work and to exchange and debate on what the upcoming priorities should be for IF in the European region.

## IF's Annual Conference

In October 2016 Ghent hosted almost 300 participants of our Turning Points Conference coorganised with the SBH team of the Ghent University and the Flemish Association for Spina Bifida and Hydrocephalus. It was already the 27th International Conference on Spina Bifida and Hydrocephalus. The debates were very innovative, frank and sometimes emotional. One of the highlights of this weekend was the official launch by HRH Princess Astrid of Belgium of the first ever Global Prevention Initiative.

Several important meetings took place: IF Youth Group, IF Global Experts Panel, Working Group International Solidarity, IF EU workshop, and the workshop for SBH clinicians on multidisciplinary care, foetal surgery and European Reference networks.

Margo Whiteford has been re-

We received a guest presenters from our partners: European Network on Independent Living (ENIL) and European Patients' Forum (EPF).



lected as IF President and four new Board members have been elected to join the IF Board for the mandate of 3 years: Tom Scott (Ireland), Aziza Mustafa Elnaeema (Sudan), Papatya Alkan Genca (Turkey), and Nicola Busata (Italy).

IF General Assembly decided to enlarge IF's membership, accepting five new SBH communities from:

- Algeria: Association des Parents et Malades Spina Bifida Bejaia
- Belgium: Association Spina Bifida Belge Francophone (ASBBF)
- Japan: Japan Council for Spina Bifida and Hydrocephalus
- Malaysia: Spina Bifida Association Malaysia (SIBIAM)
- Morocco: Association de Spina - Bifida et Handicaps Associés (SBIHAM)





# INTERNATIONAL SOLIDARITY

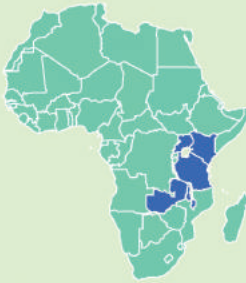




## RIGHT TO HEALTH

### Treatments

2.440 children received treatment by local partners, of which 774 ETV performed in Tanzania, Kenya, Uganda, Zambia and Malawi



2.166 children received treatment through our programme partners



### Shunts

3.930

shunts donated to 36 partners in 23 countries

### Follow up

22.348

children being followed

3.292

SHIP passport issued



655 HOME VISITS

conducted to visit

**1140**  
**children**

## COMMUNITY BUILDING

### Training

166 project staff trained

3281 parents attended 114 parent meetings

74 continence trainings organized by local partners

### Youth

282 youth participants in 29 youth meetings

10 youth as trainer

47 youth active in committees and/or board of their organization



## PREVENTION

10.611

folic acid tablets distributed

1.135.160

women reached





OUTREACH





from 2070 followers in 2015 to 2278 in 2016

**Twitter**



our ISSUU was read 3514 times in 2016

**ISSUU**



**Facebook**

from 3640 likes in 2015 on our Facebook page to 4219

**Newsletter**

our monthly newsletter grew from 5509 in 2015 to 6026 subscribers in 2016

**Youtube**

IFGlobalOrg Youtube channel received 3463 views in 2015 and grew to 6289 in 2016



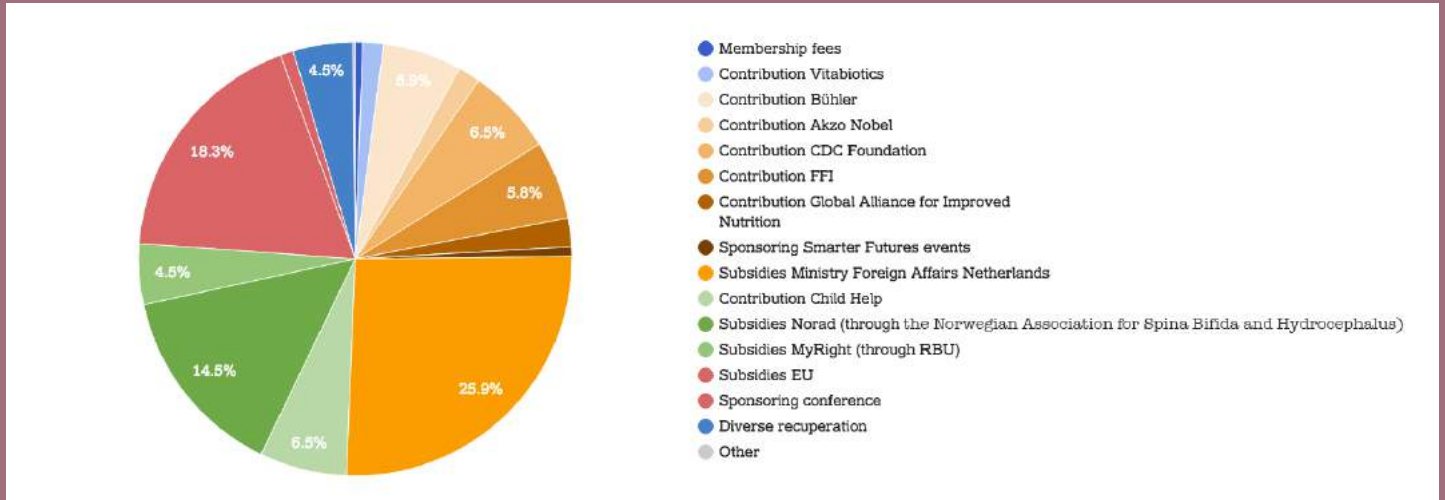


# FINANCES



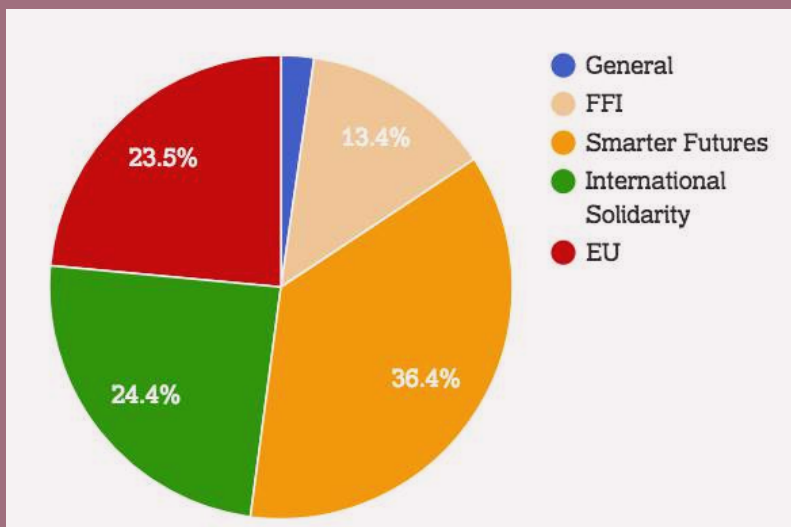
# TOTAL INCOME

1,494,733.99



# TOTAL COSTS

1,496,880.77







INTERNATIONAL FEDERATION  
FOR SPINA BIFIDA  
AND HYDROCEPHALUS

Cellebroersstraat 16 - 1000 Brussels, Belgium

T: +32 (0) 2 502 04 13

[info@ifglobal.org](mailto:info@ifglobal.org)

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

