



# 2017

## ANNUAL REPORT



INTERNATIONAL FEDERATION  
FOR SPINA BIFIDA  
AND HYDROCEPHALUS



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(Students of KASK Belgian Royal Academy of Arts)

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



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



[@ifsbh](https://twitter.com/ifsbh)



[International Federation for Spina Bifida and Hydrocephalus](https://www.linkedin.com/company/international-federation-for-spina-bifida-and-hydrocephalus/)



[@ifsbh](https://www.facebook.com/ifsbh)



[IFgloalorg](https://www.youtube.com/channel/UCGgloalorg)

# TABLE OF CONTENT

**FOREWORD** 6

**ABOUT IF** 7

**OUR MEMBERS** 14

**PARTNERSHIPS** 16

**PLAN 2015/2017: REVIEWING THE STRATEGY** 18

**INTERNATIONAL SOLIDARITY** 38

**SOCIAL MEDIA** 42

**FINANCES** 44

**2018...** 48



# FOREWORD

Dear friends,

It gives me great pleasure to write to you for the Annual Report of the last year of our strategic plan 2015-2017. It is time to look back, evaluate our achievements, challenges and opportunities and learn from our experience to establish and achieve IF's future actions and goals in the best way possible.

The Annual Report of 2017 highlights the progress of the organisation and the continuing development of activities, projects and workshops throughout the past 3 years. In 2017 we highly focused on the importance of mental health for people with spina bifida and hydrocephalus and their families, and the need for a multidisciplinary approach for everyone with SBH. On World Spina Bifida and Hydrocephalus Day, we promoted the animation "Reclaiming my health" created by IF, shared worldwide!

A highlight for me last year was the workshop that IF organised in Mombasa, Kenya. Apart from countries in Africa, participants came from the Philippines, Belgium, Norway, Sweden, Germany, Scotland, the Netherlands and Canada, it was the largest African workshop ever! It was a great experience for me to be part of this unique event.

We continued to work on global prevention and both members and partners have done a great job raising awareness worldwide, sharing the materials and information shared through the IF Global Prevention Initiative, which celebrated its second anniversary!

I would also like to thank all our Members for their hard work and their engagement to improve the quality of life of people with SBH in their countries, through advocacy, organising events and activities, and offering services and information.

Finally, I would like to express my gratitude to the IF's staff and Board of Directors for their support and good cooperation. IF will continue working hard following its mission and values to achieve a high quality of life for people with SBH in the upcoming year. Many things will be happening in 2018: European workshops in Sofia and Madrid, the IF 28th International Conference in India, and the launch of our new website, among other key events and activities. I am really looking forward to further develop IF's plans for the next years!



Margo Whiteford  
IF President



**ABOUT IF**



# WHAT IS IF?

The **International Federation for Spina Bifida and Hydrocephalus** (IF) was established in 1979 by people living with Spina Bifida and Hydrocephalus (SBH) and their families. Since then, IF Global has developed from a voluntary association into a professional Disabled People's Organisation which now includes **60 member organisations** from all over the world.

IF's members are mainly governed by adults with Spina Bifida and Hydrocephalus and parents of children living with these conditions. Members' activities are highly inclusive of children and young people and give them the opportunity to be involved in holiday camps and training workshops on independence. In most cases, IF members cooperate closely with medical and education professionals and researchers, valuing the importance of the well-being of people living with SBH.

IF is a fast-growing Disabled People Organisation and it welcomes all nationally registered organisations that share IF's vision and actively involve people with SBH in their work.

## MISSION

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 neural tube defects and Hydrocephalus by primary prevention; by raising awareness and through political advocacy, research, community building and human rights education.

## VALUES

**Human rights** approach in accordance to the UN Convention on the Rights of Persons with Disabilities (CRPD).

**Transparency and accountability** to our members, donors and external stakeholders. We work in a transparent and inclusive way.

**Participation and Inclusiveness** of different views and regional, cultural or socioeconomic specificities

**Cooperation** with international, regional and national bodies, NGOs, professional associations and other stakeholders who share our vision and goal.



# OUR BOARD



MARGO WHITEFORD  
IF President, Scotland



PAPATYA ALKAN GENCA  
Turkey



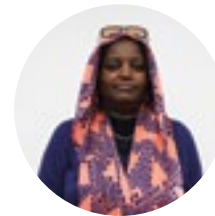
FRANTISEK HORN  
Slovakia



CATO LIE  
Norway



NICOLA BUSATA  
Italy



AZIZA MUSTAFA ELNAEEMA  
Sudan



TOM SCOTT  
Ireland



EMMA SUARDIAZ  
Spain



ELENA ZAPPOLI  
Argentina

The General Meeting held every year elects the Executive Board biennially. 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 2017, the General Meeting and the first Board Meeting took place in Berlin in May. The second Board Meeting was organised during the second EU workshop in Stockholm in November.

# IF TEAM



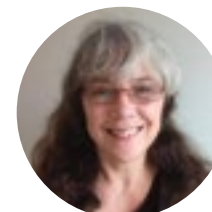
LIEVEN BAUWENS  
Secretary General



EWA KAMPELMANN  
Deputy Secretary  
General &  
Communication  
Officer



JANINA ARSENJEVA  
Europe Programme Manager



RENEE JOPP  
Information Officer



KATALIJNE VAN DIEST  
Programme Manager  
International Solidarity



CARMEN CLEMENTE  
Communication Assistant



ANNA VERSTER  
Senior Adviser on  
Food Fortification



MARTINE AUSTIN  
Programme Manager  
Global Prevention

## IN 2018, WE WELCOME:

## IN 2017 WE SAID GOODBYE TO:

## VOLUNTEERS 2017:



NUNO LOUREIRO  
Finances &  
Administration Manager



JANA MORAVCOVA  
Advocacy Officer



MARGO VANDENBROECK  
Administrator



MAIKEN BEKKE  
Communication



GIULIA BIZZOTTO  
Europe  
Programme

# OUR GLOBAL EXPERTS



MARGO WHITEFORD  
Chair



BENJAMIN WARF  
Service and Care



DAVID NOLAN MORRISEY  
Human Rights



AMY MCPHERSON  
Social Inclusion



ANNE MOLLOY  
Causes



RICHARD H. FINNELL  
Genetics

## Members of the Global Experts Network

- Ronald Afidra, FFI Africa Network Coordinator
- Quentin Johnson, FFI Training and Technical Support Coordinator
- Femke Bannink, Senior Advisor/ Researcher
- Richard Bransford, general surgeon, MD, FACS
- Myleen Christiaens, spina bifida nurse-practitioner
- 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
- Koen Sevenants, senior advisor, Development Cooperation Asia
- Carla Verpoorten, medical consultant, neuro-paediatrician
- Patrick De Vlieger, anthropology and disability
- Wouter De Groote, consultant rehabilitation, physiatrist
- Joanne Maxwell, consultant life skills and transition
- Rebecca Opetsi Alitsi, consultant CRPD / SDGs Africa

The Global Experts Panel (GEP) advises and represents IF on a broad range of matters and are considered the public spokespersons for IF on the topic of their specialty. The Panel consults the IF's Global Experts Network, and receives support from the IF secretariat. The position is considered self-funded.

On 2017, the GEP contributed to the IF response on the "Draft General Comment on Article 6 of the International Covenant on Civil and Political Rights – Right to life" for United Nations. Richard Finnell provided IF with its expertise for the next IF strategy.



# YOUTH GROUP



ELISA GARCIA DE CECA  
Spain



EGE ANLI  
Turkey



MERLIN KIZANT  
Estonia



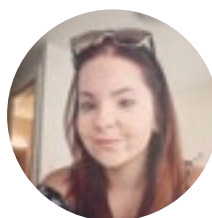
VALMAR AMMER  
(Substitute) Estonia



NELE VANHECKE  
Belgium



ADRIAN FILIP  
Poland



MIRELA BUKOVAC  
Croatia

IF would like to thank our **trainer and consultant Karina Chupina** for dedicated support and training she provided to the Youth Group in 2015-2017. Special thanks for preparing the Group members for active participation in the European Parliament of Persons with Disabilities!

## WHAT IS ADVOCACY FOR A YOUNG PERSON WITH DISABILITY?

Youth empowerment was one of the main priorities of the IF strategic plan 2015-2017. Advocacy is an action to achieve change by addressing decision-makers. Young people with disabilities, such as spina bida and hydrocephalus (SBH) face discrimination in many areas of life; therefore, understanding the basics of advocacy is important in order to fight injustice and barriers to inclusion. Once you understand your rights as persons with disabilities, you can advocate for them. You should be able to explain your rights to your community and articulate the changes that you expect from the decision-makers.

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

## **WHAT HELPS ME TO CARRY OUT (SELF-)ADVOCACY WORK?**

Merlin Kizant, Estonia:

"Firstly, I focus on things I can do, not on the things that I can't. I see myself as a person first and not my disability – I don't let my disability define me. I try to get out of my comfort zone, because this is where I discover new opportunities – and I believe I can have the same opportunities as everyone. I also accept that I am responsible for my own life. Then, it is important for me to know my rights in order to self-advocate. The most helpful approach for me was to set goals, be organised, use effective communication and take my life into my own hands. If I hadn't managed to do this and to self-advocate, I wouldn't be an elementary school teacher today".

## **HOW WAS 2017 FOR THE YOUTH GROUP?**

Mirela Bukovac, Croatia:

"It was very complete! At our first meeting in Maastricht (Netherlands), we planned the 2017 goals and activities. In order to be in line with IF's work, we decided to focus on the importance of mental health for people with disabilities. The meeting was followed by participation in a great gathering of young people called Yo!Fest, where we had a chance to learn about youth movement and Europe. For the World Spina Bifida and Hydrocephalus Day, we joined IF's social media calls for better mental health care for people with SBH.

In November we met in Stockholm (Sweden) and received training on how to be a public speaker. This was done to prepare us for an exciting opportunity to participate in the 4th European Parliament of Persons with Disabilities in Brussels. I had a chance to make a speech at the European Parliament and meet with a Croatian Member of the European Parliament. We will keep working for the rights and needs of young people with Spina Bifida and Hydrocephalus!"









**OUR MEMBERS**



## AFRICA

Algeria Association des Parents et Malades Spina Bifida Béjaïa  
Kenya Spina Bifida and Hydrocephalus Association Kenya (SHAK)  
Morocco Association Spina Bifida et Handicaps Associés au Maroc  
Nigeria Festus Fajemilo Foundation  
South-Africa Association for Spina Bifida and Hydrocephalus South Africa  
Sudan Spina Bifida Federal Association  
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)

## THE AMERICAS

Argentina Asociación para Espina Bifida e Hidrocefalia (APEBI)  
Colombia Fundación Mónica Uribe Por Amor  
Guatemala Asociación Guatemalteca de Espina Bífida (AGEB)  
Honduras Fundación Amado Josue  
Mexico Asociación Mexicana de Espina Bifida A.C (AMEB)  
Peru Asociación de Espina Bífida e Hidrocefalia del Perú (ASESBIH)  
USA Spina Bifida Association of America (SBAA); Hydrocephalus Association

## AUSTRALIA & ASIA

Australia Spina Bifida Association Queensland; The Northcott Spina Bifida Group - a program of Northcott Disability Services  
China Association of Persons with physical Disabilities  
India Spina Bifida Foundation  
Japan Spina Bifida Association of Japan; Japan Council for Spina Bifida and Hydrocephalus  
Malaysia Spina Bifida Association Malaysia (SIBIAM)  
Mongolia Mongolian Spina Bifida Foundation "Maral Angel"

## EUROPE

Austria Spina Bifida und Hydrocephalus Österreich (SB&HÖ)  
Belgium Vlaamse Vereniging voor Spina Bifida en Hydrocephalus vzw (VSH); Association Spina Bifida Belge Francophone asbl  
Bulgaria Spina Bifida Hydrocephalus Bulgaria  
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 Nationale pour le SBH  
Germany Arbeitsgemeinschaft Spina Bifida und Hydrocephalus e.V. Bundesverband (ASBH)  
Greece Hellenic Association for Spina Bifida and Hydrocephalus  
Hungary MEOSZ  
Ireland Spina Bifida and Hydrocephalus Ireland (SBHI)  
Italy Associazione Spina Bifida Italia (ASBI)  
Latvia Latvijas spina bifida un hidrocefālijas biedrība (LSBH)  
Lithuania Spina Bifida Lithuania and Hydrocephalus Association (SBHA)  
Luxembourg Association pour le Spina Bifida a.s.b.l.  
Norway Ryggmargsbrokk- og hydrocephalusforeningen  
Poland Fundacja "Spina"  
Portugal Associação de Spina Bífida e Hidrocefalia de Portugal (ASBIHP)  
Romania Asociația Română de Spina Bífida e Hidrocefalie (ARSBH)  
Russia Association of Spina Bifida and Hydrocephalus of St. Petersburg  
Scotland Spina Bifida Hydrocephalus Scotland (SBHS)  
Serbia Spina Bifida and Hydrocephalus association of Serbia  
Slovakia Slovenská spoločnosť pre Spina Bifida a/ alebo Hydrocefalus, o. z.  
Spain Federación Española de Asociaciones de Espina Bífida e Hidrocefalia (FEBHI); Associació Catalana d'Espina Bífida i Hidrocefalia (ACAEBH); Espina Bífida e Hidrocefalia Madrid; Asociación Murciana de padres con hijos de Espina Bífida e Hidrocefalia  
Sweden RBU; Spin-Off  
Switzerland Schweizerische Vereinigung zugunsten von Personen mit Spina Bifida und Hydrocephalus (SBH)  
The Netherlands BOSK Work Group Spina Bifida & Hydrocephalus  
Turkey Spina Bifida Dernegi  
UK SHINE

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



**PARTNERSHIPS**

The International Federation for Spina Bifida and Hydrocephalus holds **Special Consultative Status at the Economic and Social Council of the United Nations.**

**Since 2011** Lieven Bauwens, IF Secretary General has represented IF in the Executive Management Team of FFI and is a Board member of the International Disability Alliance (IDA). **From 2017 IF has held representation on different Boards:** Cato Lie, EDF and Lieven Bauwens, EURORDIS. Also, Ammi Andersson is the IF EURORDIS ePAG patient representative on the ERN-ITHACA Board. IF is part of the Board to the NGO Committee of Rare Diseases of Rare Diseases International (RDI).

#### **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)
- International Disability Alliance (IDA)
- Food Fortification Initiative (FFI)

#### **IF HAS OFFICIAL COLLABORATION WITH:**

- The United Nations Children's Fund (UNICEF)
- Informal relations with the 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)
- European Reference Network ITHACA

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

- Atlas Alliance, Norway
- Liliane Fonds
- Child-Help International
- Food Fortification Initiative (FFI)
- Helen Keller International (HKI)
- 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

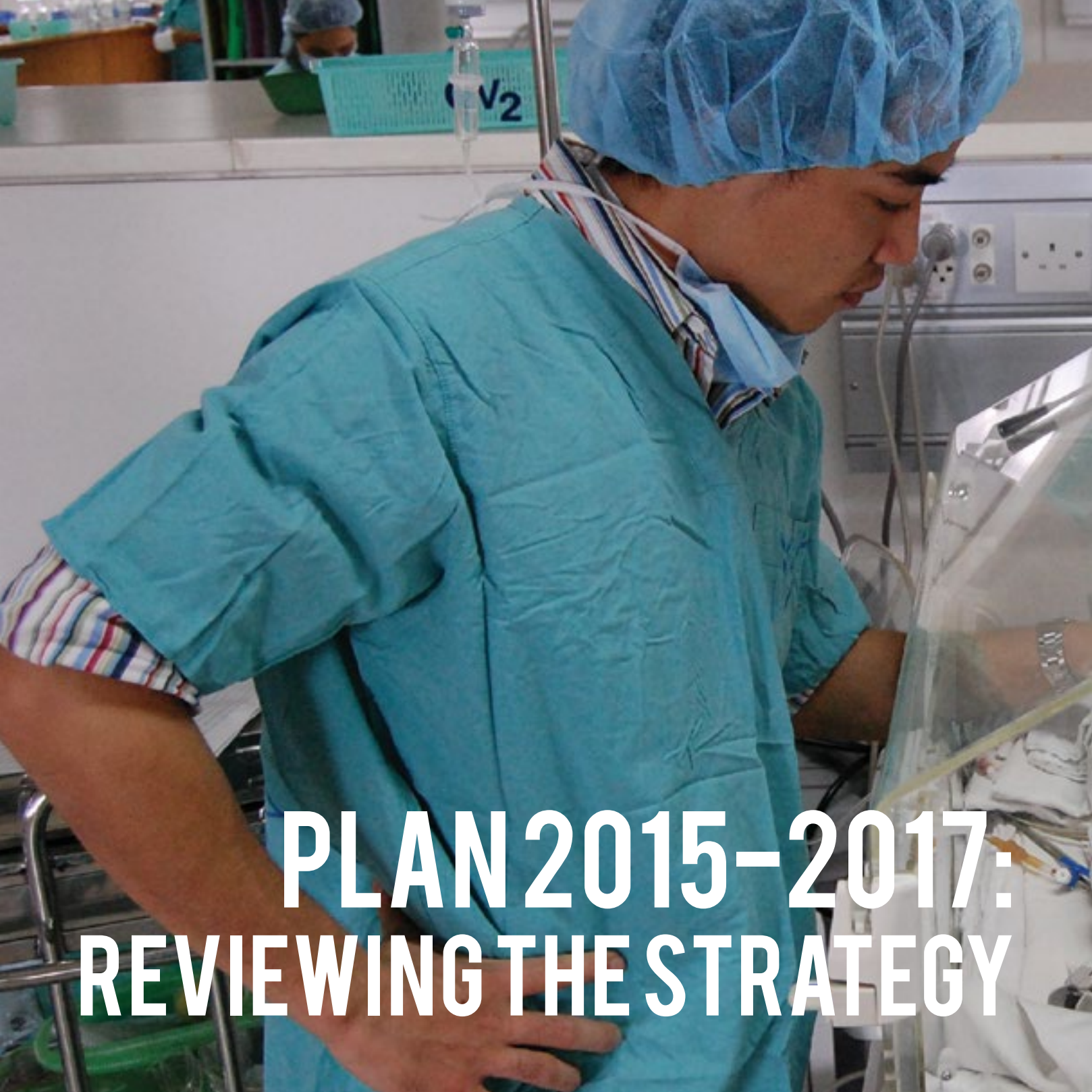
#### **IF'S PARTNERS IN DEVELOPING COUNTRIES:**

- 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 FINANCIAL CONTRIBUTIONS FROM:**

- European Union (EU)
- Bühler
- Akzo Nobel
- Vitabiotics Pregnacare
- The Global Alliance for Improved Nutrition (GAIN)
- Child - Help Belgium & International
- MyRight
- NORAD, Norway through the Norwegian Association for Spina Bifida and Hydrocephalus
- Food Fortification Initiative (FFI)
- CDC Foundation
- Ministry of Foreign Affairs of the Netherlands
- International Disability Alliance (IDA)
- Handicap International (Vietnam)



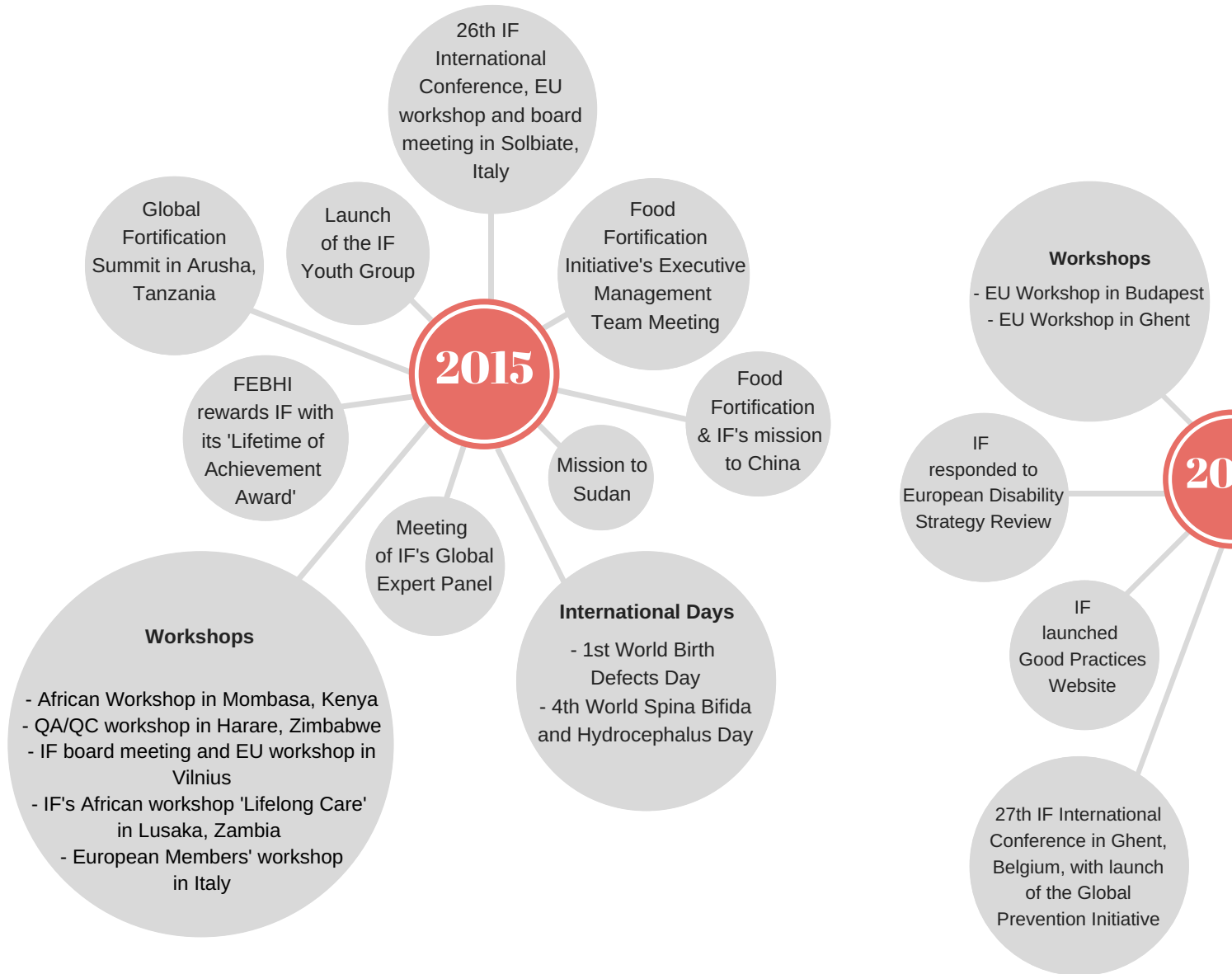


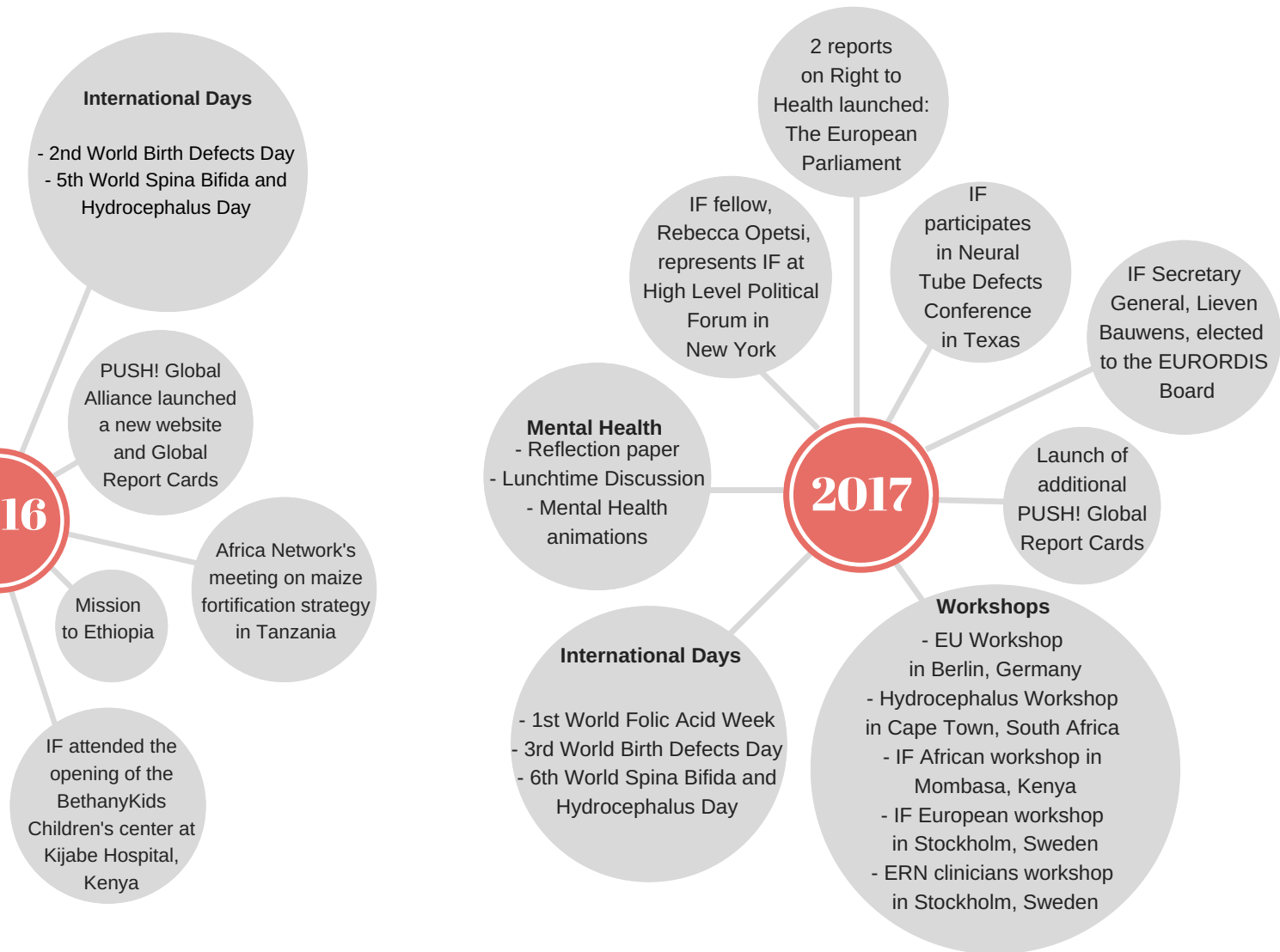
**PLAN 2015-2017:  
REVIEWING THE STRATEGY**





# STRATEGIC PERIOD AT A GLANCE





# 2017 CALENDAR

## JANUARY

- IF celebrated 1st World Folic Acid Awareness Week
- IF launched a research on Rights to Health at the European Parliament



## FEBRUARY

- Youth Group met in Maastricht to hold an election of new members and establish its plan for 2017
- IF together with 16 organisations endorsed the Joint Statement on Mental Health



## MARCH

- New PUSH! report cards of AMRO and EURO zones were launched on World Birth Defects Day
- IF volunteer, Dr. Carla Verpoorten, received SBA Lifetime Achievement Award
- IF at the 3rd conference on European Reference Networks in Vilnius
- 4 IF consultants traveled to Vietnam for Handicap International



## APRIL

- Project visit in Zambia and Malawi
- IF launched a reflection paper on Mental Health of people with disabilities
- IF co-organised a side event on independent living at Annual Convention for Inclusive Growth 2017
- IF published a response to the Progress report of the European Disability Strategy 2010-2020



## MAY

- IF Secretary General and Deputy Secretary General met with Ministry of Health and visited project in South Africa
- Smarter Futures Conference in Zambia
- IF European Members' Workshop in Berlin
- IF Global Prevention Initiative launched a leaflet on Folic Acid and its importance before pregnancy



## JUNE

- First official IF statement at Conference of States Parties to the CRPD
- IF together with its Italian member, ASBI, provided a CRPD training for young people with disabilities in Italy
- IF published an interview of Pierre Mertens with Björn Rundström, who are both former IF Presidents







#### JULY

- Rebecca Opetsi, IF fellow, at the High Level Political Forum in New York
- IF and its Argentinian member, APEBI, supported the expansion of SBH network in Ecuador and APEBI visited the project



#### AUGUST

- IF took part in the National Summit on Food Fortification in Tanzania



#### SEPTEMBER

- Volunteer from the European Voluntary Service joined the IF team in Brussels
- IF trained Macedonian organisation of Persons with Disabilities with European Disability Forum



#### OCTOBER

- IF launched an animation, "Reclaiming my health", on Mental Health Day
- World Spina Bifida and Hydrocephalus Day
- IF at Neural Tube Defects conference in Texas
- IF at Hydrocephalus workshop in Cape Town
- First anniversary of IF Global Prevention Initiative
- IF speaks at the conference on European Accessibility Act in Tallinn, Estonia



#### NOVEMBER

- IF European Members' workshop in Stockholm
- ERN Spina Bifida clinicians workshop in Stockholm
- IF speaks at International Conference on Birth Defects and Disabilities
- Advocacy mission to support the development of multidisciplinary care in Zagreb
- African workshop, Mombasa, Kenya



#### DECEMBER

- IF Youth Group at the 4th European Parliament of Persons with Disabilities
- Rebecca Opetsi, IF fellow, held a presentation on 'Self advocates in relation to CRPD and SDG' at a Youth Workshop organized by Bethany Kids and SHAK in Kenya

# 2017 WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY

On October 25, 2017 IF celebrated the 6th World Spina Bifida and Hydrocephalus Day (WSBHD). The aim was to raise awareness about the importance of taking care of both the physical and mental health of people with Spina Bifida and Hydrocephalus, and the well-being of their families and carers. The importance and significance of mental health should not be underestimated, which is why we support an **integrated approach** to Spina Bifida and Hydrocephalus care, which includes psychologists and mental health professionals.

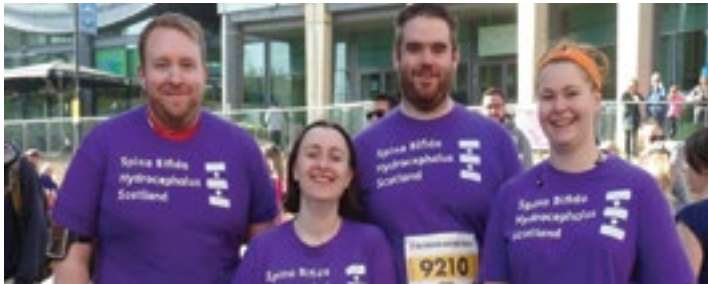
30 IF members organised different activities around the world for WSBHD 2017! Some of the activities were:

On behalf of **SBAH Slovakia** presented strategies for prevention of NTDs to the private companies; in South Africa, our member **ASBAH-SA** gathered some health professionals to get in touch and speak with young people with SBH; **HISBAS from Serbia** organised an event for donors; **SHINE from UK** held an awareness week and some buildings were illuminated to promote well-being for people with SBH; APEBI from Argentina organised workshops, shows and games mainly for children; **Festus Fajemilo Foundation from Nigeria** was represented at Lagos State of Office of Disability Affairs to raise awareness on SBH and they got media coverage from Lagos Television; our spanish members **AMUPHEB and FEBHI** published a video supporting IF's campaign.




[www.worldspinabifidahydrocephalusday.com](http://www.worldspinabifidahydrocephalusday.com)



# OUR MEMBERS ACTIVITIES



Spina Bifida and Hydrocephalus Awareness Week 2017  
incorporating  
World Spina Bifida and Hydrocephalus Day  
25<sup>th</sup> October 2017



#sbhiawarenessweek



**World Spina and Hydrocephalus Awareness Day**

[www.sbhi.ie/aw2017](http://www.sbhi.ie/aw2017)





#WSBHD - 25th October 2017  
 Raising awareness of Spina Bifida &  
 Hydrocephalus in Scotland - @SBHScotland

Spina Bifida  
 Hydrocephalus  
 Scotland



Text SBHS17 £5 to 70070 to donate to SBH Scotland and help us make a difference today. Thank you.



A l'occasion de la journée Mondiale de la Spina Bifida  
**L'Association Spina Bifida Maroc & Le CHU Ibn Rochd Casablanca**  
 et Handicaps Associés



Organisent

**Une journée portes ouvertes**

le 25 Octobre 2017 - de 9h à 13h  
 au CHU Ibn Rochd Casablanca

Sensibilisation

Prévention

Intégration

Pour plus d'infos

Tél: (+212) 660 21 33 94  
 contact@spinabifidamaroc.ma  
 www.spinabifidamaroc.ma





Some disabilities, such as Hydrocephalus, can affect executive function, which may trigger onset of anxiety or depression.

#WSBHD #MentalHealth



# PRIMARY PREVENTION



## O B J E C T I V E S

- 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.

## K E Y O U T C O M E S

2nd World Folic Acid Awareness Week organised in January 2018

Smarter Futures Training of Trainers in Nairobi

Article about Smarter Futures in "Milling and Grain" Magazine

1 Smarter Futures workshop in Zambia on fortification

Reach of 164,974 achieved, in 327 cities, with the first World Folic Acid Awareness Week Thunderclap campaign in January 2017

425 subscribers to the General Prevention Initiative newsletter

2 articles published on prevention

Publication on folic acid translated into 4 other languages, with more in the pipeline

# ADVOCACY

## Global Prevention Initiative (GPI)

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28th October 2017 marked the **1st anniversary of the IF's Global Prevention Initiative (IFGPI)**. We published a press release and shared a social media toolkit, encouraging people to celebrate the anniversary with us! Along 2017, the IFGPI has supported the **Food Fortification Initiative**, and regional fortification activities, such as the **Smarter Futures** project in Africa.

We were also working hard **to engage the milling industry**, (having been called upon twice in 2017 to write an article for industry trade press), by highlighting the potential impact of this simple but important policy measure in human terms. The IF GPI campaign continued to reach out like-minded organisations, health professionals, researchers and individuals to help share information, campaign for mandatory fortification in countries where such measures haven't yet been adopted, and promote the need for further research into both Spina Bifida and Hydrocephalus prevention.

# Folic Acid

What every woman needs to know  
*before* becoming pregnant



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



# LEARNING & EXCHANGE

## Smarter Futures

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Smarter Futures is a public-private-civic partnership that supports similar partnerships of flour millers, governments, vitamin and mineral suppliers, international organizations, and academic institutions to make fortification of wheat flour a reality in Africa. The aim of Smarter Futures is to improve health in Africa through the enrichment of wheat and maize flour with essential vitamins and minerals.

The partners involved are: the **Food Fortification Initiative, AkzoNobel, Helen Keller International**, and **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.



In May, Smarter Futures held a **workshop on Quality Assurance and Quality Control (QA/QC) for Flour Fortification in Zambia**. The workshop was designed to ensure that maize and wheat flour fortification programs were implemented correctly to achieve an effective public health impact. In July, a **Training of Trainers workshop** was held in Nairobi, Kenya to increase the capacity of flour fortification stakeholders to plan for, implement, and monitor well-developed, feasible, and efficient flour fortification programs.

In August, a **National Summit on Food Fortification in Tanzania** brought together government, industry leaders, millers, international organisations and stakeholders involved in fortification efforts. Representatives of the IF member, Association for Spina Bifida and Hydrocephalus Tanzania (ASBAHT) presented the need for folic acid fortification to the Tanzanian Vice-President.

In October, Smarter Futures' partner Helen Keller International (HKI) and the Tanzanian Food Fortification Alliance supported a study on the effects of a large-scale wheat flour folic acid fortification program among women of reproductive age in urban Tanzania.

In November, HKI and FFI co-organised a meeting on Rice Fortification – An Opportunity to Improve Nutrition in West Africa, in Dakar, Senegal. The meeting addressed rice fortification technologies, supply chain and other relevant topics.

At the end of the year, the **Milling and Grain Magazine** featured an article on the history, work and achievements of Smarter Futures.





# RIGHT TO HEALTH



## O B J E C T I V E S

- Children and adults with spina bifida and hydrocephalus enjoy timely access to high quality, appropriate, affordable healthcare and rehabilitation, without discrimination or prejudice.
- Information about the rights of children and adults with SBH in a healthcare setting is widely available for people with SBH and their families, medical and para-medical professionals and political decision-makers in appropriate and accessible formats.

## K E Y O U T C O M E S

Mental health and well-being of people with Spina Bifida and Hydrocephalus: 1 animation (both in English and Spanish), 1 reflection paper and 1 lunchtime discussion

1 toolkit for the WSBHD

Presentation of IF'sv research on right to health and cross-border healthcare

Study visit to a multidisciplinary clinic

1 African workshop

1 response on the European Accessibility Act (EAA)

# ADVOCACY

## Multidisciplinary care: Mental Health

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In 2017, IF began a new chapter in its history by exploring the **mental health and well-being of persons with SBH and their families**. The first step was to endorse, together with 16 other organisations, the **Joint Statement on Mental Health**, which was originally prepared by Mental Health Europe and EUFAMI. On World Health Day (April 7th), IF published a **reflection paper** and invited everyone to a lunchtime discussion, kicking off the debate and invite opinions.

For **World Mental Health Day** (October 10th), IF launched an animation highlighting the importance of an integrated approach to the well-being of persons with SBH and their families. To continue working on mental health, IF initiated an **informal international network of psychologists and mental health professionals** to unite a wide range of health professionals experienced in providing therapy for people with SBH. The aim of the network is to exchange knowledge and professional experience and advocate for inclusion of mental health professionals in SBH multidisciplinary clinics. IF also focused on mental health during the 2017 **World Spina Bifida and Hydrocephalus Day**, encouraging its members to join efforts to achieve an integrated approach to SBH care.

## Research on cross-border access to healthcare

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On January 27, IF presented the research undertaken 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”** at the European Parliament. The event was co-hosted by Jana Zitnanská MEP, Nessa Childers MEP and Diane Dodds MEP, together with the European Disability Forum and European Patients' Forum.

## EU advocacy: European Accessibility Act (EAA)

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In 2017, IF continued its advocacy to improve accessibility of goods and services for people with disabilities in Europe. It joined forces with other organisations to lobby for a strong and ambitious European Accessibility Act. We collected evidence of barriers that people with spina bifida and hydrocephalus experience in accessing transport, services, facilities and leisure and mobilised our national members to improve the legislative proposal and utilizing the media to make our concerns known. In March, IF was an active and visible participant of a **public demonstration** in front of the European Parliament in Brussels, calling for a strong Act.

The legislative process is not finished, and as of December 2017, we had seen both commendable improvements and worrying setbacks to the original legislative proposal. In 2018, we will continue monitoring the situation and taking appropriate action to guarantee obstacle-free Europe for people with SBH.

# PROCESSES

## European Reference Networks

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During the 3rd Conference on European Reference Networks (ERNs) in Vilnius, Lithuania, 24 ERNs for rare and complex conditions were officially launched on March 9, 2017. IF was represented by its **Advocacy Officer Jana Moravcova** and our **European Patients Advocacy Group (ePAG) member Ammi Andersson** of our Swedish member RBU at the event.

On March 10, Ammi took part in the **first official Board meeting of the ERN-ITHACA**, the ERN on congenital malformations and rare intellectual disability, and she also joined the separate launch meeting of the ERN-ITHACA on September 25 in Manchester. Throughout the year, 3 online meetings were held with Spina Bifida clinicians involved in the ERN-ITHACA as part of our Associated Group within this ERN.

# LEARNING & EXCHANGE

## Visit to Spinalis

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During the EU Workshop in November in Stockholm (Sweden), IF's members and Spina Bifida clinicians had the chance to visit the impressive **Spinalis Rehabilitation Centre**. The Spinalis Foundation opened their new premises last summer and we had the chance to discover the renovated buildings while we were there. The visit was organised in close cooperation with our member Spin-Off in Sweden. We learned that all the rooms had built-in advanced technology which should benefit people with Spina Bifida and with spinal cord injuries on a daily basis. Furthermore, they kindly introduced us to their daily work programme of training, treatments and research. We highly appreciate Spinalis' excellent work and innovative ideas that stand out as a good example for all of us.

## African Workshop

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From 2-4 November 2017 more than 90 participants gathered for IF's biennial African Workshop, the largest workshop in the history of IF. The workshop theme was **"Convention on the Rights of Persons with Disabilities & Access to Health"**

Participants came from Uganda, Kenya, Tanzania, Sudan, Zambia, Malawi, South Africa, Nigeria, Ethiopia, the Philippines, Belgium, Norway, Sweden, Germany, Scotland, the Netherlands and Canada. Amongst them were parents, children and young adults, SHIP coordinators and other experts working with people with spina bifida and hydrocephalus.

# COMMUNITY BUILDING



## O B J E C T I V E S

- 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.

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

1 training on project proposal for IF EU members

IF joined a workshop in Croatia on multidisciplinary care

2 workshops for IF EU members

1 training for young people with SBH on the UN CRPD

12 monthly Members Voice and 12 general newsletters

19 SBH clinicians participated in ERN workshop

1 training on Mental Health for EU members

New report cards on PUSH! platform



# ADVOCACY & COMMUNICATION

## Mission to Croatia

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Always attuned to its members' needs, IF supported an initiative to establish of a **multidisciplinary care centre for people with SBH** in Croatia. A series of meetings, including a visit of a medical facility and exchange with healthcare professionals, a discussion with Croatian public officials and a meeting with Croatian families affected by SBH was organised in November. The activity, co-organised by IF and its Croatian member "Aurora", was joined by SBH organisations from the neighbouring Serbia and Montenegro.

The outcomes of the activity include familiarity with the multidisciplinary model of care by professionals, establishment of working relations with the government officials, and increased regional cooperation between the organisations in the Western Balkans region.



## PUSH! Global Alliance

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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 March 2017, PUSH! Global Alliance announced the launch of the report cards of the **WHO regions AMRO (The Americas) and EURO (Europe)**, thus making data available for all the countries in the world. Also, an article about the Global Report Cards, "**Scorecard for spina bifida research, prevention, and policy – A development process**" was published online in Preventive Medicine.

Why are the report cards important for your country?

- Clear information: The report cards provide country and regional snapshots of indicators grouped by World Health Organization (WHO) regions.
- Common platform: the alliance will serve as a platform for countries and organisations to move to action, further efforts and accelerate change.
- Exchange of experience: easy access to all the report cards to learn from other countries' actions on SBH.

# LEARNING & EXCHANGE

## Training for EU members

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In 2017 we organised two European workshops for IF EU members: the first one took place in **Berlin** and the second one in **Stockholm**. Our members got an update on IF's work and we discussed the next priorities for IF in the European region. In Berlin, within the context of a **training on mental health**, IF invited Dr. Peter McGovern, a psychiatrist working with the World Health Organisation, to give a training session on the human rights approach to mental health. Through the **training on projects' proposal**, our members learnt how to conceptualise a project proposal when applying for funding. Also, in Stockholm, IF presented to its members the first ideas and work done for the **new IF website** that will be launched in 2018.

In June, 11 young people with SBH from all Italy's regions gathered in Varese to receive **training on independent living skills, their human rights and advocacy**. The training, co-organised by IF and its Italian member ASBI and conducted by a group of national and international experts, was aimed at providing young people with skills necessary to lead an independent life and advocate for their rights in education, employment, community living and social life.

The main **outcome** of the training was a personal advocacy action plan that each participant prepared to strategically address the barrier they identified at the local level. The training also contributed to empowering young people with disabilities and preparing the future leaders of the international SBH movement.

## Expanding SBH network into Ecuador

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APEBI, our Argentinian member, is dedicated to build a Latin American and the Caribbean Network for Spina Bifida and Hydrocephalus to improve the quality of life for people living with these conditions and their families.

Throughout a **workshop in Ecuador** back in september 2017 where the participants listed goals such as raising folic acid awareness, share information about Spina Bifida and Hydrocephalus, make other parents aware of the network, improve the relationship doctor-patient and organise same-day appointments at the children's hospital. All goals that the LATAM Network will continue working on.

Furthermore, the Network is developing a LATAM and The Caribbean youth group for people with SBH.







**INTERNATIONAL  
SOLIDARITY**



# UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (UNCRPD)

## Rebecca Opetsi received IDA Fellowship

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IF and the International Disability Alliance (IDA) granted a fellowship to the activist Rebecca Opetsi Alitsi to work on the UNCRPD and Inclusive Development starting from April 2017.

The main objective of the fellowship was to **support the national SBH organisations of persons with disabilities in Tanzania (ASBAHT) and Kenya (SHAK)** in awareness raising on the provisions and implementation of the UNCRPD. The focus of activities was towards people with disabilities and their families, health care providers, teachers, legal professionals and community leaders with the aim of enabling them to use the UNCRPD and Sustainable Development Goals (SDGs) for inclusion of people with disabilities.



Rebecca started publishing articles on her own **blog** and provided training at two different workshops. The first one was a **CRPD workshop for the Association of Spina Bifida and Hydrocephalus of Tanzania (ASBAHT)** in Kilimanjaro (Tanzania). The aim of the workshop was to train both ASBAHT parent leaders and youth leaders on CRPD/SDG on how they can use the treaties to create inclusive communities. The workshop was attended by 30 participants. The second one was held from 2-4, November 2017 during the **IF Biennial African workshop in Mombasa, Kenya** and it was attended by 90 participants. Rebecca presented on the CRPD and SDGs during the youth workshop that was organized by Bethany Kids and SHAK in Kenya in December 2017.

From the 9th to the 20th of July 2017, **Rebecca represented IF at the High Level Political Forum on Sustainable Development Goal** in New York to ensure that countries take the rights of people with disabilities into account when implementing the SDGs and when reporting on their progress through Voluntary National Reports.



# INCLUSIVE EDUCATION

## 'No One Left Behind' project

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IF and Festus Fajemilo Foundation (FFF) started a project that will be developed from 2017 until 2019. The project, implemented in Nigeria, aims to equip children with SBH and their families with the skills and knowledge necessary to fully participate in society, with emphasis on right to health and education.



In July 2017, FFF organised in Lagos (Nigeria) a **skill acquisition training for 16 mothers of children with SBH and 1 adult with SB**. The purpose was to empower them so they can generate income to support the education of their children.

FFF implemented a **training on continence management for health workers** to improve the health conditions of children with SBH in collaboration with SHINE, IF's member from the UK, who supported with 2 trainers in continence management. The participants developed skills on Clean Intermittent Catheterization (CIC), bowel wash out and oxybutin instillation.

## 'Community Based Inclusive Development for Children with SBH in Uganda'

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This project, funded by Norad through IF and its member in Norway, aimed to promote inclusive education and accessibility in 5 primary schools in Wakiso district by the collaboration with SHYNEA Uganda, Katalemwa Cheshire Home and University of Ghent.. Among the main activities, 10 parents received a training on how to be actively involved in their children's inclusive education and SHYNEA received media coverage during WSBHD.



## International Solidarity

### Right to Health

**22.348**

Children being followed

**655**

Home visits conducted to visit **1.140** children

**3.292**

SHIP passport issued

**3.930**

Shunts donated to **36** partners in **23** countries in collaboration with Child-Help

### Prevention

**1.135.160**

Folic acid tablets distributed

**10.611**

Women reached



### Community Building

**74** continence trainings organized by local partners

**166** project staff trained

**2.206** parents attended **49** parent meetings

**27** youth meetings with **242** participants

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

**10** youth as trainer

**2.166**

New children received treatment through our programme partners

**474**

ETV operations performed in Kenya, Uganda, Zambia and Malawi





**SOCIAL MEDIA**

# SOCIAL MEDIA OUTREACH



Twitter: 2048 followers



Facebook: 4.894 likes



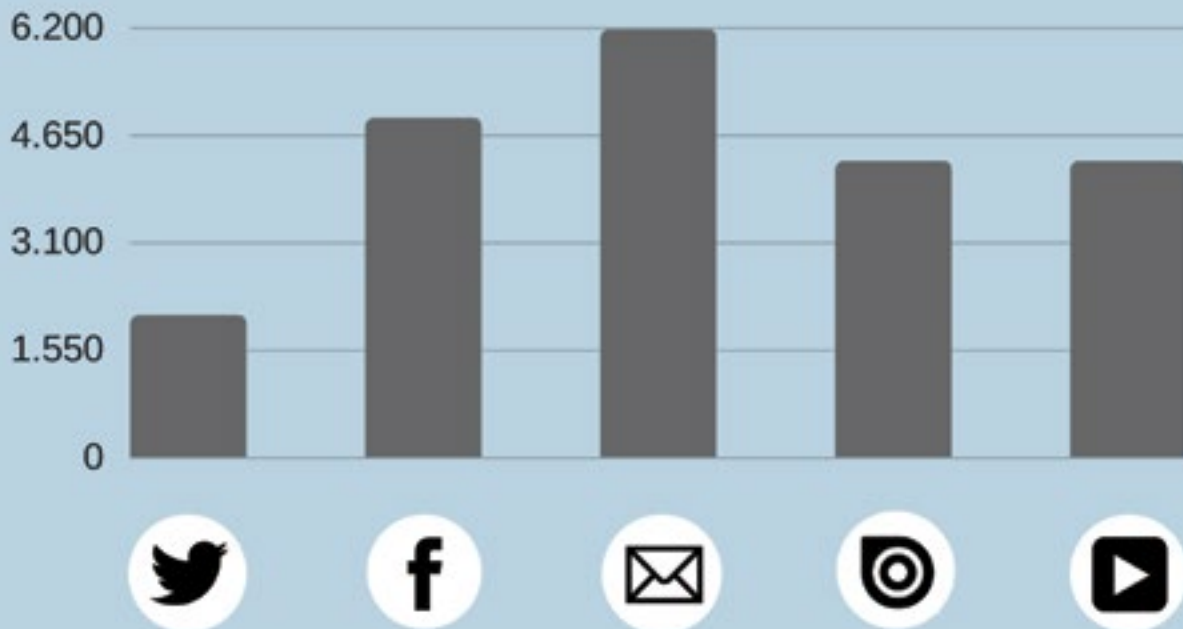
Newsletter: 6.171 subscribers



ISSUU: 4274 reads



YouTube: 4478 views









**FINANCES**

# TOTAL INCOME

<b>INCOME (€)</b>	<b>1.331.311,71</b>
General Income	1.305.592,21
Membership fees	7.520,00
Contribution FFI	44.446,16
Contribution Bühler	65.887,34
Contribution Vitabiotics	33.280,35
Contribution Akzo Nobel	25.000,00
Contribution Child Help	193.359,27
Contribution CDC Foundation	7.197,97
Contribution Global Alliance for Improved Nutrition	45.816,76
Contribution International Disability Alliance	29.316,88
Consultant Handicap International (Vietnam)	23.091,99
Subsidies Norad (through RHF)	250.463,15
Subsidies MyRight (through RBU)	68.101,56
Subsidies EU	274.524,00
Subsidies Ministry Foreign Affairs Netherlands	224.646,67
Sponsoring Smarter Futures events	12.940,11
<b>Diverse recuperation</b>	<b>24.226,39</b>
<b>Financial Income</b>	<b>1.453,11</b>
<b>RESULT</b>	<b>-39.816,21</b>

# TOTAL EXPENSES

<b>ALL COSTS (€)</b>	<b>1.371.127,92</b>
General Costs	911.679,17
Housing costs (rent, energy, cleaning)	20.688,20
Office supplies	6.473,69
Publications	6.806,98
Communication costs (website, telephone, postal costs)	11.051,52
Shipping costs	1.508,99
Membership of associations	2.324,00
Payroll costs	8.038,23
Bookkeeping	5.120,02
Audit	1.784,75
Insurance	1.353,27
Official documents (visa)	2.046,34
Consultant - Global Prevention Initiative	23.732,20
Consultant - Uganda (Flour Fortification Africa)	48.979,99
Consultant - CRPD	3.600,00
Consultant - IT	1.364,88
Consultant - Vietnam (Flour Fortification Asia)	5.349,02
Consultants - Flour Fortification (Smarter Futures)	24.105,89
Consultant - Youth Group (EU)	3.300,00
Consultants - EU	2.075,00
IDA Fellowship	4.612,59
Mental Health Animation	5.300,00
Other fees	5.392,00
Travel	194.205,77
Accommodation and subsistence	59.682,22
Conferences - Workshops	145.117,73
Medical material to projects	20.517,25
Salaries in projects	96.170,80
Training in projects	105.456,99
MyRight Organization Building	46.504,00
Other costs projects	49.016,65
<b>Salary Costs</b>	<b>451.796,86</b>
<b>Depreciations</b>	<b>1.423,53</b>
<b>Taxes</b>	<b>106,99</b>
<b>Financial Costs</b>	<b>6.121,37</b>





2018...

# WHAT IS COMING IN 2018?

- Preparatory work for the IF comparative study on availability of integrated care in Europe
- IF will continue its work on mental health of people with disabilities, specifically with SBH
- IF, together with its member Spina Bifida Foundation from India will organise the 28th IF International Conference on Spina Bifida and Hydrocephalus in New Delhi, India
- This year, IF will launch a new website, more accessible and user-friendly
- Rebecca Opetsi will continue her work on the UNCRPD and Inclusive Development
- 2018 World Spina Bifida and Hydrocephalus Day: "SBH throughout the lifespan"
- 3rd training of young Europeans with SBH on independent living skills, human rights and self-advocacy
- Tailored support to IF members on advocacy strategies for access to continence management procedures
- First ever high-level discussion on all aspects of ageing with spina bifida and hydrocephalus

**These are just some of the activities and projects for 2018, we will keep you posted along the year!**

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**Thank you for supporting IF in 2017 and let's continue working together for the better health and well-being of people living with Spina Bifida and/or Hydrocephalus and their families!**





**IF** SBH INTERNATIONAL FEDERATION  
FOR SPINA BIFIDA  
AND HYDROCEPHALUS