Working to reduce the incidence of spina bifida and hydrocephalus by primary prevention and to improve their quality of life.
MESSAGE FROM THE PRESIDENT

Dear friends,

2015 was a year of change for all of us. IF has been working hard to ensure that people with spina bifida and/or hydrocephalus (SBH) are well represented and their issues recognised internationally.

First and foremost, I would like to thank our members, partners and supporters. Reaching our objectives for the past year would not have been possible without you. Your involvement truly shows that you share our mission and make us want to advance in our work around the world to help people with SBH fully enjoy their rights. At the end of the year we welcomed six new member organisations and we have been active at international and regional levels providing our support and sharing good practices.

In 2015, we adopted a new strategic plan for 2015-2017. It has been a good opportunity for us to revaluate our achievements, challenges and opportunities and to integrate them into a strategy that shapes our future actions.

IF is constantly evolving. The activities highlighted in this report are a testimony to the progress that has been made. New developments include the creation of the IF Youth Group; our involvement in ensuring that the particular needs and views of youth with SBH are recognised.

We have also initiated projects related to advance the greatest benefit to those affected by spina bifida and hydrocephalus through the PUSH! Global Alliance platform. It is of utmost importance that IF keeps its focus on both prevention and care, providing its expertise and guidance towards the improvement of the quality of life of people with SBH and their families in developed and in developing countries.

Finally, I thank the IF staff for their support during the past year and look forward to ongoing productive cooperation in the future.

Margo Whiteford, IF President
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1. KEY FACTS

"LIFETIME ACHIEVEMENT AWARD" FROM FEBHI
Conference and workshops

The 26th International Conference on Spina Bifida and Hydrocephalus, Solbiate Olona

More than 100 participants
44 speakers

EU Workshop, Vilnius

30 participants
4 World Cafés

EU Workshop, Solbiate Olona

5 thematic Workshops, Solbiate Olona

Trainings

23 July: Webinar on EU funds with Alessandro Negro “EU FUNDS MAPPING Overview of European Funding Opportunities for IF Global and Members”

15 to 20 December: Webinar on Social media: part I with Tom Scott from the Spina Bifida Hydrocephalus Scotland
The 2015 recipient of the IF Annual Award was **Pierpaolo Mastroiacovo**, Professor of Pediatrics; Director of the Alessandra Lisi International Centre on Birth Defects and Prematurity (ICBD), and the Centre of the International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR).

IF President Margo Whiteford presented him with the award during the 26th International Conference on Spina Bifida and Hydrocephalus.

“I am very pleased and really honoured to receive this Award. It brings me to the beginning of my career when I was deeply involved in caring for children with congenital disabilities, including spina bifida and hydrocephalus. I am glad to receive this award for my current main interest: prevention of birth defects. Last, but not least, I see this Award as an Award to the International Clearinghouse for Birth Defects Surveillance and Research, which was very active to organize and support training courses on surveillance of birth defects, particularly for developing countries.”  - **Prof. Mastroiacovo**
Our online audience/outreach

- Subscribers:
  - 2013: 3063
  - 2014: 5211
  - 2015: 5509

- Likes:
  - 2013: 1840
  - 2014: 9889
  - 2015: 3640

- Followers:
  - 2013: 323
  - 2014: 1127
  - 2015: 2070

- Views:
  - 2014: 4138
  - 2015: 3463

- Page views:
  - 2014: 48718
  - 2015: 54521
25 October is **World Spina Bifida and Hydrocephalus Day** to raise awareness about SBH and to advocate and promote the rights of persons living with these conditions.

This year, the day had special significance because it was the first following the adoption of the UN Committee on the Rights of Persons with Disabilities (UNCRPD) final recommendations to the EU, September 2015, and the adoption of the new Agenda for Sustainable Development Goals (SDGs), October 2015, the most inclusive for people with disabilities. The SDGs emphasise the inclusion and participation of persons with disabilities as one of the keys to end poverty and discrimination.

Persons with SBH continue being denied information about treatments, are financially discriminated when travelling across EU borders in search of better healthcare, and have difficulties finding access to the appropriate treatment and care.
Kenya

World Spina Bifida and Hydrocephalus Day
This Sunday, to show our infant to spread awareness more effectively every single day. Spina Bifida Hydrocephalus Ireland (SBHI) will officially launch a new, refreshed logo and, later in the week, a wonderful new website!

All will be revealed here on Facebook, so watch this (web) space!

Ireland

Spain/Madrid

This week in Spina Bifida and Hydrocephalus Awareness Week

Shine is coordinating its week with its members and supporters in the UK and Northern Ireland...

"Shine has put us in touch with lots of other people and families living with spina bifida and hydrocephalus. We look at events as a very special and unique opportunity that have given us lots of love, support, advice and most importantly, hope and inspiration for our child’s future."

If you would like to support Shine’s ongoing work, please text AWAK15 to 70870

A big thank you from everyone at Shine for your generosity.

Colombia

United Kingdom

Sweden

Lithuania

Sudan

Bulgaria
2. ABOUT US, MISSION AND VALUES
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.

MISSION

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

VISION

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

VALUES

Human rights: promotion and protection of human rights of people with SBH in accordance with the UNCRPD is our highest value.

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

Participation: we take the views of children and adults with SBH, and their families into account and rely on them in our work.

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

Inclusiveness: we respect the regional, cultural and socioeconomic specificities of our global members, and promote a tailored approach to working on SBH issues.
OUR BOARD 2015-2016

- Margo Whiteford, President, Scotland
- Thelma Cloake, Secretary, Ireland
- Cato Lie, Treasurer, Norway
- Lumbwe Chiwele, Zambia
- Santosh Karmarkar, India
- František Horn, Slovakia
- Emine Nurdan Anli, Turkey
- Emma Suardiaz, Spain
- Elena Zappoli, Argentina

OUR SECRETARIAT

- Lieven Bauwens: Secretary General
- Janina Arsenjeva, Europe Programme Manager
- Jana Moravcova: Advocacy Officer
- Jackie Bland: Development Director
- Renée Jopp: Information Officer
- Ewa Kampelmann, Marta Anguera: Communications Officers
- Anna Maarit Paakkulainen/ Margo Vandenbroucke: PA/Administrator
- Katalijne Van Diest: Programme Manager, International Solidarity
- Martine Austin: Programme Manager - Global Prevention
- Anna Verster: Senior Advisor, Food Fortification

Communication trainee 2015: Inma López
IF volunteers in 2015: Eric Holdtgrefe, Vera Costa
EXTERNAL COOPERATION

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 EU 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 the Food Fortification Initiative.

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.

The International Federation for Spina Bifida and Hydrocephalus has vastly enlarged its international network.

IF is member of:
- European Disability Forum (EDF)
- European Patients Forum (EPF)
- Eurordis
- The Internarnational Disability Alliance (IDA)
- International Disability and Development Consortium (IDDC)

In 2015 IF was cooperating with the following international bodies:
- European Union (EU)
- Council of Europe (CoE)
- The United Nations Children’s Fund (UNICEF)
- United Nations Economic and Social Council (UN ECOSOC)
- World Health Organisation (WHO)
- European surveillance of congenital anomalies (EUROCAT)
- Food Fortification Initiative (FFI)
- The Global Alliance for Improved Nutrition (GAIN)
- European Disability Forum (EDF)
- European Patients’ Forum (EPF)
- The European Organisation for Rare Diseases (EURORDIS)
- International Disability and Development Consortium (IDDC)
- European Union Agency for Fundamental Rights (FRA)
- Liliane Fonds
- Bethany Kids
- CURE International
- Association of Volunteers in International Service (AVSI)
- WHO Partnership for Maternal, Newborn & Child Health (PMNCH)
- Handicap International (HI)
- Helen Keller International (HKI)
- Atlas Alliance
- MyRight

Companies
- Akzo Nobel
- B BRAUN Medical
- Bühler
- Surgiwear
We are actively engaged in a number of working and expert groups to which we bring the knowledge and needs of the families of people with SBH across the world. We want to stay informed about current developments and trends of importance in the field of Spina Bifida and Hydrocephalus, and encourage further research to improve the quality of life of persons born with these conditions and reduce the incidence of Spina Bifida and Hydrocephalus by primary prevention. To this end we are currently developing a Global Experts Network on Spina Bifida and Hydrocephalus, which is steered by our Global Experts Panel.

Composition of the Global Experts Panel:
- Margo Whiteford, Chair
- Benjamin Warf, Services and Care
- David Nolan Morrissey, Human Rights
- Amy McPherson, Social Inclusion
- Richard H. Finnell, Genetics
- Anne Molloy, Causes

Composition of the Global Experts Network:
- Femke Bannink, Senior Advisor/ Researcher
- Richard Bransford, general surgeon, MD, FACS
- Myleen Christiaens, consultant on Spina Bifida
- Filippo Ciantia, tropical medicine
- Kordelia Fischer-Borchert, consultant, community-based rehabilitation
- Philippe Gillis, consultant paediatrics and tropical medicine
- Helen Healy, consultant life skills and transition
- Bo Hjelt, consultant fundraising and general management

- 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

Global liaisons:
- Marisol Hernandez, IF liaison in Buenos Aires
- Liu Jiarong, IF liaison in Beijing

FFI Consultants:
- Ronald Afidra, FFI Africa Network Coordinator
- Quentin Johnson, FFI Training and Technical Support Coordinator
## IF Calendar

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<tr>
<td>PUSH Executive Committee meeting, Boston</td>
<td>ICBDSR/CDC/WHO Training on Birth Defect Surveillance</td>
<td>World Birth Defects Day (3 March)</td>
<td>FFI EMT meeting</td>
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<td>Face-to-face meeting of IF’s Global Experts Panel</td>
<td>Working group International Solidarity</td>
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<td>EU High Level Group on Disability</td>
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<td>MAY</td>
<td>JUNE</td>
<td>JULY</td>
<td>AUGUST</td>
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<td>QA/QC workshop in Harare, Zimbabwe</td>
<td>FEBHI rewards IF with its “Lifetime Achievement Award”</td>
<td>Webinar on EU funds SRSBH conference</td>
<td>Configuration of the IF Youth Group</td>
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<td>Launch of the G4 Alliance</td>
<td>EDD 2015</td>
<td>IF Board meeting EU workshop, Vilnius</td>
<td>Response to the list of issues on the European Union Report to the UNCRPD</td>
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<td>Mission to Sudan</td>
<td>COSP CRPD</td>
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<td>SEPTEMBER</td>
<td>OCTOBER</td>
<td>NOVEMBER</td>
<td>DECEMBER</td>
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<td>Global Fortification Summit, Arusha, Tanzania</td>
<td>26th International conference &amp; EU workshop, Solbiate Olona IF Board meeting</td>
<td>IF’s Annual African workshop “Lifelong care” in Lusaka, Zambia</td>
<td>Webinar on Social Media: part I</td>
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<td>International Conference on Birth Defects</td>
<td>WSBH day (25 Oct)</td>
<td>FFI EMT meeting</td>
<td>FFI/IF mission to China</td>
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<td>3rd Global Experts Panel meeting</td>
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3. WIDENING OUR NETWORK

57 MEMBERS
6 NEW MEMBERS IN 2015
Algeria Association des malades de Spina Bifida de Mostaganem - **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** Vlaamse Vereniging voor Spina Bifida en Hydrocefalus 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** A.S.B.I. Associazione Spina Bifida Italia - **Japan** 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. - **Mexico** Asociación Mexicana de Espina Bífida A.C. (AMEB) - **Mongolia** Mongolian Spina Bifida Foundation “Maral Angel” - **The Netherlands** BOSK Work Group Spina Bifida & Hydrocephalus - **Nigeria** Festus Fajemilo Foundation - **Norway** Ryggmarvsbrokk- og hydrocephalusforeningen - **Peru** Asociación de Espina Bifida e Hidrocefalia del Perú (ASESBIH) - **Poland** Fundacja “Spina” - **Portugal** Associação e Spina Bifida e Hidrocefalia de Portugal (ASBIHP) - **Romania** Asociatia Romana de Spina Bifida 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 spolocnost’ pre Spina Bifida a/ alebo Hydrocefalus, o. z. - **South Africa** Association for Spina Bifida and Hydrocephalus - **Spain** Federación Española de Asociaciones de Espina Bifida e Hidrocefalia (FEBHI); Associació Catalana d’Espina Bifida i Hidrocefalia (ACAEBH); Asociación Madrileña de Espina Bifida e Hidrocefalia (AMEB) Asociación Murciana de padres con hijos de Espina Bifida 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
4. INTERNATIONAL DEVELOPMENT

2940 NEW CHILDREN JOIN SHIP

4585 SHUNTS
**Children in follow up**
- 26,116 children being followed in their rehabilitation and development
- 417 home visits conducted and 810 children visited

**Training**
- 57 trainings continence management organised
- 141 staff trained
- 4,641 participants in parent meetings
- 19 trainings staff with 141 participants

**Prevention**
- 1,091,408 folic acid tablets distributed
- 48 trainings organised on prevention with 2,016 participants

**Treatment**
- 3,020 joined the programmes in 14 countries
- 873 ETV operations performed in Mbale, OURS, Katalemwa, Kenya, Blantyre

**Youth programme**
- 23 youth meetings and 181 participants
- 18 youth as a trainer from OURS, Katalemwa, Kenya, Moshi, Khartoum, Zambia and PASHL
- 26 youth active in committees
5. IF IN NUMBERS
Total income
1.297.362,93

Total costs
1.287.664,73

INCOME
- Smart Futures: 35%
- NORARD: 26%
- Other grants: 1%
- EU-progress: 30%
- Memberships fees: 0%

COSTS
- Staff: 56%
- Conferences - meetings: 18%
- Communication & website costs: 3%
- Travel & subsistence costs: 14%
- Others: 5%
- Office: 4%