



# ANNUAL REPORT 2012

## Finding our way



INTERNATIONAL  
FEDERATION  
for  
SPINA BIFIDA  
and  
HYDROCEPHALUS

Created in 1979, the [International Federation for Spina Bifida and Hydrocephalus](#) (IF) is the **global umbrella organisation** for 50 national and regional Spina Bifida and Hydrocephalus (SB-H) organisations. Improving the quality of life of people with SB-H and decreasing the incidence of Spina Bifida through primary prevention are main motivations for every action IF undertakes.

IF is an **International NGO** with special category consultative status with the Economic and Social Council of the United Nations and participatory status at the Council of Europe, recognized as one of 7 key EU networks on disability.

IF's activities are focused on the dissemination of information and expertise throughout the world to families, individuals, professionals and volunteers involved in the field of Hydrocephalus and Spina Bifida.



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# Our mission

## improve

the quality of life of people with SB/H

and the quality of service delivered to people with SB/H worldwide

## advocate

for primary prevention and campaign to influence international policies on primary prevention

## support

parents groups, international organizations and people with SB/H in developing countries through projects of early detection, treatment and rehabilitation

## encourage

the establishment and cooperation of new groups and national organizations of people with SB/H and their parents

## promote

the exchange of knowledge and good practices at an international level and the work with international bodies

## stimulate

research and discussion on ethics to ensure that people with SB/H are included in all international programmes

## Contents

### THE INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS IN 2012

7

Our key achievements in 2012

Facts and Figures

Members

Board of directors

Staff members

Representation

IF Consultative team

Partners



## OUR PRIORITY AREAS:

PREVENTION 12

HUMAN RIGHTS 16

INTERNATIONAL SOLIDARITY 22

NETWORK DEVELOPMENT 27

FINANCIAL RESULT IN 2012 31

## Message from our president “Finding our way”

For the last time as president, Pierre Mertens sums up the highlights of the year.

After 18 years of serving IF as president I write for the 18th and last time the introduction to the annual report. It is amazing that our organisation had only **two presidents in its 35 years of existence**. It reminds us of some countries where the law was changed to allow the president to stay for another term. We did the opposite, we changed the statutes to force the IF network to have **more rotation in its board** and this means that I have to step down in 2013.

At our annual conference ‘Finding Our Way’ in Stockholm, the General meeting elected **Margo Whiteford** as IF’s Vice-President so that she could take over from me at our conference in Izmir in 2013. Weekly Skype meetings ensure a smooth transition.

**Björn Rundström**, IF founder and first president, was invited as the guest of honour to this conference. He served as the first IF president for 17 years and at the opening of the conference this historical photo was taken.

It is with great faith that I will hand over this function to Margo. **The background of the first two chairpersons was having daughters with Spina Bifida. The next president IS a daughter with Spina**

**Bifida**. I could not have wished for more. Margo chaired the Scottish association for many years and as a medical doctor she will connect the scientific and clinical world with the persons and families with Spina Bifida and Hydrocephalus. Because in this changing world **we need to unite all forces to push our goals forward. We are PUSH = People United for Spina Bifida and Hydrocephalus**, a movement that cannot be stopped.

2012 was not a year of transition. It was again a year of growth where IF’s recognition as key player in the international world was confirmed. Some examples of what you can read in this report: IF in collaboration with FFI hosted a workshop at the World Health Forum Gastein and co-organised a high-level panel at the European Development Days.

We presented a position paper on ageing in the European Parliament in Strasbourg where we also organised an exhibition of photographs from our member organisations, showing the true face of Spina Bifida. A second exhibition focusing on our work in Africa, was shown in the central hall of the WHO premises in Geneva.

IF made major steps to be more active in Asia and Latin America with liaison people in Beijing and Buenos Aires. IF signed Memorandum of Understanding with the China Disabled Persons Federation with regard to better access to care for persons with Spina Bifida in this huge country.

Looking back over these 35 years of growth and achievements I feel most proud of the work we were able to start in Africa. We proved that in the context of the developing world good care could be provided **FOR** and **WITH** our target group. Some of the first adults with Spina Bifida we helped now finished university and are working as staff members of our African projects.



In 2012 IF expert and neurosurgeon Ben Warf, now associate professor at the Harvard Medical School, received the prestigious MacArthur Foundation Fellowship for the pioneering work he did with us in Uganda.

**I want to thank all of you for the trust you have given me all these years. I feel extremely honoured that you all have offered me the opportunity to lead this wonderful network for so many years.**

Through Child-Help, a small Belgian nongovernmental organisation, I will continue the solidarity work for Spina Bifida and Hydrocephalus in developing countries. And of course I will do this in close cooperation with the IF network.

Keep in touch!

**Pierre Mertens**  
**IF President**



## Our key achievements in 2012

A successful year for the International Federation for Spina Bifida and Hydrocephalus

**We celebrated for the first time a very successful World Spina Bifida and Hydrocephalus Day** with the purpose of raising visibility of issues connected to SB/H. The World Day was a significant reminder to the public and policy makers that it is imperative to increase awareness and improve the lives of people with these impairments.

**We organised the well received exhibition “UNFOLD their potential, (Y)our Return on Investment” at the European Parliament** thanks to the involvement of our members who are continuously developing skills in advocacy and campaigning at national and international level.

**We achieved a record-breaking donation of 3300 shunts in Africa**, which is an obvious sign of the growth of the programme. Over 4000 children are in continence management follow-up and over 16000 in neurosurgical follow-up. This is a huge group of children who will be our next ambassadors.

We received **substantial funds from the Dutch government** to be even more influential in our actions on prevention through flour fortification in developing countries. Flour fortification with at least folic acid and iron is gaining enormous momentum around the world, and IF is closely connected to this important network.

We published the widely spread **Position Paper on Ageing** under the framework of the **2012 European Year for Active Ageing**. This research substantiated the issue of active ageing, and issues

of overcoming the challenges of ageing faced by people with Spina Bifida and Hydrocephalus.

We developed the **encompassing regional strategies** that resulted in the Memorandum of Understanding signed with the Chinese government and an increased network in Latin America.

We participated in many interesting **high-level events** like the European Development Days and together with the FFI we organised a workshop at the European Health Forum.

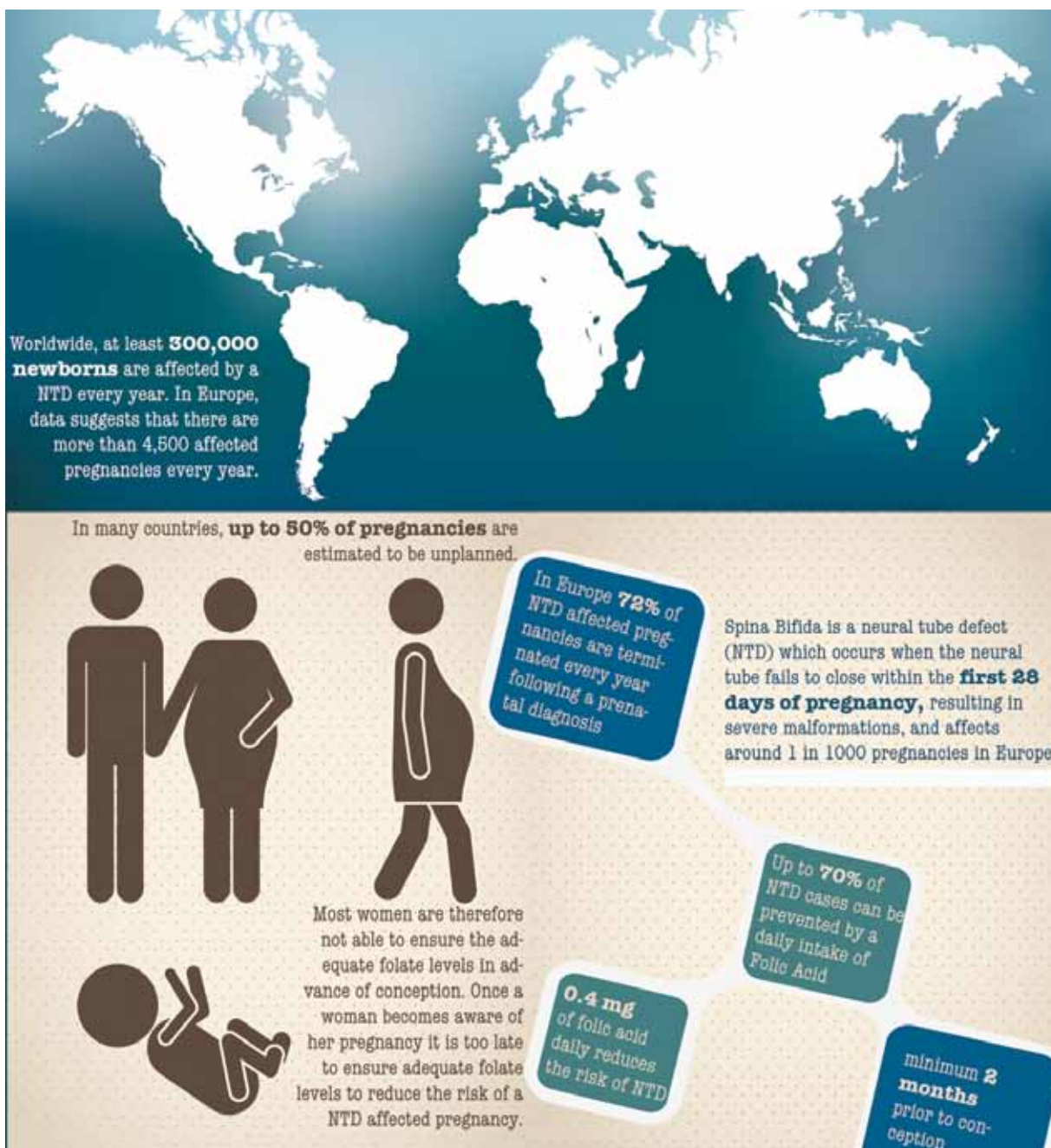
We became a member of the **Global Partnership on Children with Disabilities** and the **Partnership for Maternal, Newborn, and Child Health**.

Three organisations representing people with SB/H in Bulgaria, Columbia and Madrid, Spain became **new members** of the IF family.

## Facts and Figures on Spina Bifida and Hydrocephalus

Thanks to the continuous advances in medicine, healthcare services for people with Spina Bifida and Hydrocephalus have considerably improved. Despite this

progress, many children and adults living with Spina Bifida and Hydrocephalus still do not have access to the right treatment and care services. Moreover, stigma and discrimination remain a reality in many countries because people are not aware about the facts regarding Spina Bifida and Hydrocephalus and ways to prevent neural tube defects.



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# Members of the International Federation for Spina Bifida and Hydrocephalus

**Algeria** Association des malades de Spina Bifida de Mostaganem

**Argentina** Asociación Para la Espina Bífida e Hidrocefalia (APEBI)

**Australia** Spina Bifida Association Queensland

**Austria** Spina Bifida und Hydrocephalus Österreich (SB&HÖ)

**Belgium** Vlaamse Vereniging voor Spina Bifida en Hydrocephalus vzw (VSH)

**Brazil** Associação de Espinha Bífida e Hidrocefalia do Rio de Janeiro (AEBH)

**Bulgaria** Spina Bifida Hydrocephalus Bulgaria

**Canada** Spina Bifida and Hydrocephalus Association of Canada (SBHAC)

/ Association de spina-bifida et d'hydrocéphalie du Canada (ASBHC)

**Colombia** Fundación Sin Barreras, 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

**\*India** Spina Bifida Foundation

**Ireland** Spina Bifida and Hydrocephalus Ireland (SBHI)

**Italy** A.S.B.I. Associazione Spina Bifida Italia

**Japan** Spina Bifida Association of Japan

**Luxembourg** Association pour le Spina Bifida a.s.b.l.

**\*Kenya** Spina Bifida and Hydrocephalus Association (SHAK)

**\*Lithuania** Spina Bifida ir Hidrocefalija asociacija

**Mexico** Asociación Mexicana de Espina Bífida A.C. (AMEB)

**The Netherlands** BOSK Work Group Spina Bifida & Hydrocephalus

**\*Nigeria** Festus Fajemilo Foundation

**Norway** Ryggmargsbrokk- og hydrocephalusforeningen

**Peru** Asociación Peruana de Espina Bífida e Hidrocefalia Arequipa (APEBHI), Asociación de Espina Bífida e Hidrocefalia del Perú (ASESBIH)

**Poland** Stowarzyszenie Chorych z Przepukliną Oponowo-Rdzeniową R.P. (ASBP); 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** Scottish Spina Bifida Association (SSBA)

**Serbia** Spina Bifida and Hydrocephalus association of Serbia

**Slovakia** Slovenská spoločnosť pre Spina Bifida a/ alebo Hydrocephalus, o. z.

**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)

**Sudan** Spina Bifida Federal Association

**Sweden** RBU

**Switzerland** Schweizerische Vereinigung zugunsten von Personen mit Spina Bifida und Hydrocephalus (SBH)

**Turkey** Spina Bifida Derneği

**UK** SHINE

**USA** Spina Bifida Association of America (SBAA)

\* joined in 2013



## Board of directors

In 2012, the IF board met in Cumbernauld, Scotland (April), Stockholm, Sweden (June) and in Strasbourg, France (October). It includes the following members:

Mr. Pierre Mertens, President. Belgium  
 Ms. Eli Skattebu. Norway  
 Mrs Elena Zappoli. Argentina  
 Mrs. Thelma Cloake. Ireland  
 Mrs. Eva Toft. Sweden  
 Mr. David Diaz Garcia. Spain  
 Mrs. Margo Whiteford. Scotland  
 Mr. Douglas Sorocco. United States  
 Mrs. Jackie Bland. United Kingdom

## Staff members

Brussels office:

Mr. Lieven Bauwens - Secretary General  
 Mrs. Katalijne Van Diest – Development Cooperation Coordinator  
 Mrs. Stefania Pirani - European Projects Coordinator  
 Mrs. Renée Jopp - Information Officer  
 Mr. Badr Mouhcine / Mrs. Ewa Kampelmann - Communications Officer  
 Mrs. Valeria Randon / Mrs. Anna Maarit Paakkulainen – Administrative Officer  
 Mrs. Anna Verster - Senior Advisor Flour Fortification

International Staff:

Mrs. Femke Bannink - Senior Advisor/ Researcher, Kampala, Uganda  
 Mrs. Rebecca Nakkito - Administrative Assistant. East-Africa, Kampala, Uganda  
 Mrs Liu Jiarong - liaison in Beijing, China  
 Mrs Marisol Hernandez - liaison in Buenos Aires, Argentina

IF volunteers:

Mr. Zjuul Devens  
 Mrs. Vanessa Eyegehe  
 Mrs. Brigid Glennon  
 Mr. Eric Holdtgrefe  
 Mrs. Viviane Lepingle  
 Mrs. Greta Van Seghbroeck  
 Mrs. Mol Mertens

## Representation

The International Federation for Spina Bifida and Hydrocephalus holds Special Consultative Status at the Economic and Social Council of the United Nations (renewed in 2007) and Participatory Status at the Council of Europe (renewed in 2009). Through the PROGRESS programme, IF holds a privileged relationship with the European Commission. Since 2011 Lieven Bauwens represents IF in the Executive Management Team of the Flour Fortification Initiative.

## IF Consultative team

- Dr. Richard Bransford  
general surgeon, MD, FACS
- Dr. Jan Cordonnier and Mrs. Annick Uytterhaegen - laboratory
- Mrs. Myleen Christiaens  
consultant continence management
- Dr. Filippo Ciantia  
tropical medicine, Expo 2015
- Mrs. Kordelia Fischer-Borchert  
consultant community-based rehabilitation
- Dr. Philippe Gillis  
consultant paediatrics and tropical medicine
- Frank De Graeve  
communications advice
- Mrs. Helen Healy  
consultant life skills and transition
- Mr. Bo Hjelt  
consultant fundraising and general management
- Ms. Sofie Van Houtte  
user representation
- Prof. Dr. Emmanuel Keirse  
user counselling
- Dr. Joe Mulinare  
prevention expert, Centers for Disease Control and Prevention
- Dr. Dan Poenaru  
medical consultant, paediatric surgeon
- Mr. Koen Sevenants  
senior advisor Development Cooperation Asia
- Dr. Carla Verpoorten  
medical consultant, neuro-paediatrician
- Prof. Dr. Patrick De Vlieger  
anthropology and disability
- Prof. Benjamin C. Warf  
medical consultant, paediatric neurosurgeon, ABNS, ABPNS

## Partners

The International Federation for Spina Bifida and Hydrocephalus has vastly enlarged its international network. In 2012 IF was supported by the following bodies:

### International Institutions

- 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)

### International Organisations

- European surveillance of congenital anomalies (EUROCAT)
- Flour Fortification Initiative (FFI)
- European Disability Forum (EDF)
- The European Organisation for Rare Diseases (EURORDIS)
- International Disability and Development Consortium (IDDC)

### Other International NGOs

- Liliane Fonds
- Bethany Kids
- CURE International
- Association of Volunteers in International Service (AVSI)
- International Christian development organisation (CBM)
- Handicap International (HI)

### Companies

- B BRAUN Medical
- Bayer Healthcare
- Bühler
- Surgiwear
- Akzo Nobel



# PREVENTION

Although the primary prevention of Spina Bifida and Hydrocephalus in developed countries has significantly improved, it remains the key challenge of IF's work.

## Showing support for prevention

IF's involvement in activities highlighting folic acid's ability to reduce the risk of NTD-affected pregnancies is long-standing.

IF has a strong history of promoting folic acid supplements, but in 2005 we also started to **engage in support for flour fortification**.

Here is a short synopsis of IF's encouragement for primary prevention through this public health initiative.

**2005:** IF lobbied MEPs requesting mandatory food fortification with folic acid

**2005:** IF Policy Statement on mandatory food fortification adopted

**2007:** The Flour Fortification Initiative (FFI) and IF hosted the European Meeting on Mandatory Flour Fortification in Brussels, Belgium

**2008:** Toolkit for Flour Fortification in Europe presented during a workshop in Lisbon, Portugal

**2008:** IF participated in the First African Flour Fortification Workshop in Arusha, Tanzania

**2009:** IF engaged in the Smarter Futures (Africa) project together with BOSK, FFI and AkzoNobel, with financial support from the Dutch Government

**2010:** IF took part in the 2nd African Flour Fortification Workshop in Cape Town, South Africa

**2011:** Lieven Bauwens, IF General Secretary, became a member of FFI's Executive Management Team

**2012:** Smarter Futures project scaled up with additional funding from the Dutch Government

**2012:** FFI's Europe Associate began direct partnership with IF

**2012:** IF and FFI organized a workshop at the 15th European Health Forum Gastein to advocate for fortification in the region

## Enhanced Partnership for Fortification: Focus on Europe

**July //** IF and FFI added a new dimension to their partnership when the IF Secretariat welcomed Becky Handforth, FFI's Europe Associate, to Brussels.

FFI's decision to open a position in Europe came after conducting country-specific assessments in 2011 on population health indicators, NTD rates, milling industries and potential partnerships in the region. In addition to the collaboration with IF in Europe, FFI also cooperates with UNICEF to engage in fortification activities in Central and Eastern Europe and the Commonwealth of Independent States (CEECIS).

In 2012, FFI played a significant advocacy role in Europe. Advocacy missions were held with stakeholders from the public and private sectors in Azerbaijan and Georgia. In June, two consecutive workshops were hosted for countries in the CEECIS region to inform the medical community about flour fortification and to increase the capacity of governments to monitor flour fortification programs at a national level.

Though some technical support was also provided in 2012, it is expected that these efforts will expand next year along with advocacy efforts in other countries.

## IF&FFI workshop at 15th European Health Forum Gastein

Crisis and Opportunity: Health in an Age of Austerity

**October 3-6** // During the 15th European Health Forum Gastein, IF together with the Flour Fortification Initiative (FFI) hosted a workshop on Flour Fortification.

Topics were presented by:

- Francesco Branca, Director of Nutrition for Health and Development at WHO,
- Scott Montgomery, Director of Flour Fortification Initiative,
- Sue Horton, Chair in Global Health Economics at the Centre for International Governance Innovation,
- William Dietz, Former Director of the Division of Nutrition, Physical Activity and Obesity at Centers for Disease Control and Prevention USA,
- and Dr. Margo Whiteford, IF vice president.

The aim of the workshop was to **support flour fortification efforts in Europe** and to convince country leaders that measures should be adopted, especially in the current age of austerity.

The workshop covered the following topics: improvement of nutrition in Europe, overview and benefits of flour fortification in Europe, the economic impact of flour fortification, common myths related to flour fortification, and a case study of neural tube defects.

The event was well received by senior policy and decision-makers representing politics and governments at EU, national and regional levels, business and industry, health care funders and service providers, civil society, as well as experts and researchers in health care and public health.

## European Development Days 2012

Resilience: the Nutrition Dimension – Bridging the gap between knowledge, policy and action

**October 16 - 17** // Within the framework of the European Development Days 2012 IF teamed up with UNICEF, UN's World Food Program, Save the Children, Concern Worldwide and Development Policy Forum in organising a debate on nutrition.

This high-level panel examined the policy areas, programme interventions and actors that need to be involved in **addressing undernutrition** comprehensively and effectively. It focused on the roles of the EU and other actors, such as the private sector and looked at the examples from Asia and Africa. The panel proposed recommendations to the various actors on the improvements in the areas of mainstreaming nutrition across sectors, ensuring policy coherence and regarding specific actions it should take.

Nutrition provides the critical foundation for optimal human health and development. Despite that, the undernutrition rates are still staggering. Almost 1 billion people are undernourished, while a further 2 billion suffer from micronutrient deficiencies. Malnutrition is an underlying cause of one-third of child deaths (2,7 million children) each year. Simply put, that is five children per minute. Child mortality is further related to birth defects, such as neural tube defects, which are highly preventable if the mother has sufficient intake of folic acid prior to conception.

## 6th European Conference on Rare Diseases and Orphan Products

### Spina Bifida & primary prevention

**May 23 - 25** // The conference organised by EURORDIS was a real platform covering all rare diseases across all EU countries. It brought together over 600 stakeholders from academics, health care professionals, industry, policy makers and patients' representatives. The conference was organised on 7 themes covering over 30 unique and informative sessions and panel discussions on research, development of new treatments, health care, social care, information, public health and support at European, national and regional levels. One of the themes discussed was information & public health. Participants focussed on primary and secondary prevention. IF constantly promotes folic acid as an effective way of preventing neural tube defects. IF President Pierre Mertens presented **Spina Bifida as an example of a rare condition that can greatly benefit from the dissemination of information and increased awareness of primary prevention.** Improvement of periconceptional folate levels among women of childbearing age needs a combination of counselling, correct intake of Folic Acid and fortified staple food. IF presented a poster related to the report "Act against Europe's most common birth defects: one year on - Defining Neural Tube Defect prevention strategies in Europe". Part of IF's presentation on Spina Bifida & primary prevention was featured in an article by Orphanet Journal of Rare Diseases.

## IF joins the Partnership for Maternal, Newborn & Child Health

The Partnership for Maternal, Newborn & Child Health (PMNCH) enlarged in 2012 by involving IF as its new member.

The Partnership is an alliance of approximately 450 organisations, responding to the rapidly changing global health demands, mobilising its members and partners to accelerate progress towards the Health Millennium Development Goals (MDGs), in particular 4 & 5.

The PMNCH supported and facilitated the development of the "Global Strategy for Women's' and Children's Health". Leaders from governments, international organisations, businesses, academia, philanthropy, health professional associations, organised civil society, and the private sector contributed to the development of this joint strategy recognizing that **the health of women and children is a crucial condition under the progress of all MDGs.**

IF is working with PMNCH for improvement of health and life of women, newborns and children. Currently, IF is collaborating with 12 partners in 7 developing countries, and is providing support and advice to over 40 other developing countries. This program aims to improve inclusion of people with Spina Bifida and Hydrocephalus and improve access to and knowledge of medical and lifelong care. In order to accomplish this, IF partners with health facilities, community and outreach programs, and DPOs representing people with SB/H and their families. Thanks to these actions more than 16.500 children are currently receiving follow-up care.



# HUMAN RIGHTS

Fighting for the rights of people with Spina Bifida and Hydrocephalus on the international scene.



## Unfolding the potential: 1st International Spina Bifida and Hydrocephalus Day

**October 25** // The World Spina Bifida and Hydrocephalus Day designated in 2011 during IF's General Assembly in Guatemala was a great opportunity to raise awareness and understanding about Spina Bifida and Hydrocephalus globally. It also served as means to advocate and promote the rights of persons with these impairments. The SB/H Day was officially celebrated for the first time on 25 October 2012 all over the world.

IF, together with member associations and with the patronage of MEP Diane Dodds, celebrated this exceptional day with the exhibition marking the final of the photo contest "**UNFOLD their potential, (Y)our Return on Investment**". The exhibition was launched in the European Parliament in Strasbourg by Mrs. Diane Dodds (Non-attached MEP), Mr. Karl Freese (Health Information, DG Health and Consumers, European Commission), Mr. Jan Jařab (Regional Representative of the UN Office

for Human Rights), and Mr. Pierre Mertens (IF president). Dr. Margo Whiteford (IF vice president) announced the winning picture of the IF competition and handed the prize to Inés Boekholt-Förderer, president of the Swiss Spina Bifida and Hydrocephalus Association.

Three topics were at the core of the exhibition:

- healthcare for any child with Spina Bifida and Hydrocephalus;
- multidisciplinary care for all people with Spina Bifida and Hydrocephalus throughout their lifespan;
- inclusion and employment for people with Spina Bifida and Hydrocephalus.

Prior to the exhibition, **11 representatives of IF member associations held bilateral meetings with more than 26 MEPs from their respective countries** to advocate and push the issues related to people with SB/H forward on the political agenda. On this occasion the Parliament's magazine issued two articles dedicated to Spina Bifida and Hydrocephalus.

Many IF members shared their SB/H Day activities on: [www.worldspinabifidahydrocephalusday.com](http://www.worldspinabifidahydrocephalusday.com)

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



## WHO celebrates 1st International Spina Bifida and Hydrocephalus Day

**October 25** // The World Health Organisation (WHO) welcomed the first International Spina Bifida and Hydrocephalus Day by hosting an **IF exhibition in Switzerland**.

The photos displayed were the result of a project conducted by IF together with the Belgian Royal Academy for Fine Arts (Koninklijke Academie voor Schone Kunsten – KASK).

The photographer, Io Cooman, followed the life of Ambrose, a 29-year old occupational therapist working for Organized Useful Rehabilitation Services (OURS). **Ambrose's motto is: "disability is not inability" and he works tirelessly to improve the quality of life of people with SB/H.** He provides families with correct information, facilitates access to rehabilitation services including surgery when necessary, and supports families to stimulate and realize their child's potential.

The photo exhibition showed the wonderful work of Ambrose but also the world of Moussa, Chisa and Justice. Moussa is a boy of ten, who lived in isolation for many years until he received treatment and care. Chisa, thanks to the training in continence management, will go to school next year. Justice, abandoned by her mother, has now received a second chance at a family by being fostered by a couple that know how to take care of a child with a disability. WHO has an important role to play in the prevention of Spina Bifida and Hydrocephalus and equally in the treatment and care of children affected by these conditions. The World Health Assembly adopted resolution WHA 63.10: birth defects (prevention and quality of life) in 2010. WHO released new Guidelines on Community-Based Rehabilitation in 2010 that can help workers like Ambrose enhance the quality of life for people with disabilities and their

families, including children with Spina Bifida and Hydrocephalus, meet basic needs, and ensure inclusion and participation. IF provides support to OURS (financial support, medical material and training) and works closely with WHO.



## Global Partnership on Children with Disabilities

September 14-15 // IF joined the Global Partnership on Children with Disabilities, a network of more than 100 organisations, including international NGOs, local NGOs, Disabled People's Organisations, governments, academia and the private sector, working to advance the rights of children with disabilities at the global, regional and country levels. With a rights-based approach, the Partnership provides a platform for advocacy and collective action to ensure the rights of children with disabilities are included and prioritized by both the Disability and Child Rights Movement.

The inaugural Forum of the Partnership was held in New York, where for the first time the Partners came together to discuss ways to advocate for an inclusive post-2015 agenda; establish four task forces with the aim to influence the mainstreaming of disability rights into global child-focused agendas, namely in nutrition, education, humanitarian action and assistive technology; and discuss collaboration at the country-level in Haiti, Rwanda, Turkey, Azerbaijan, Malawi, Mozambique and Bangladesh.

## 5th Session of the Conference of States Parties to the UNCRPD

**September 12 - 14** // The 5th Session of the Conference of States Parties included four formal meetings, two round tables entitled "Accessibility and technology" and "Children with disabilities"; an interactive dialogue on the implementation of the Convention on the Right of Persons with Disabilities (UNCRPD) by the UN system, and an informal meeting entitled "Women with disabilities" with participation of representatives from civil society organisations. The Spina Bifida and Hydrocephalus community was represented

by IF secretary general Mr. Lieven Bauwens.

The Convention on the Rights of Persons with Disabilities and its Optional Protocol entered into force on 3 May 2008. The Convention follows decades of work by the United Nations to change attitudes and approaches to persons with disabilities. The Convention is intended as a human rights instrument with an explicit social development dimension. It adopts a broad categorization of persons with disabilities and reaffirms that **all persons with all types of disabilities must enjoy all human rights and fundamental freedoms**. It clarifies and qualifies how all categories of rights apply to persons with disabilities and identifies areas where adaptations have to be made for persons with disabilities to effectively exercise their rights, as well as areas where their rights have been violated, and where protection of rights must be reinforced.

The Conference of States Parties is made up of signatories to the Convention, and has the authority to consider any matter with regard to implementation of the Convention. IF holds Special Consultative Status with the Economic and Social Council of the United Nations (ECOSOC) since 1991. Consultative status provides NGOs with access not only to ECOSOC, but also to its many subsidiary bodies, to the various human rights mechanisms of the United Nations, as well as special events organized by the President of the General Assembly.

## Ageing with Spina Bifida and Hydrocephalus

In 2012 IF has published a pioneering position paper: Overcoming the challenges of ageing faced by people with Spina Bifida and Hydrocephalus. It outlined the challenges faced by people with these disabilities as they are becoming older in three key areas: employment, social inclusion and health. It presented recommendations for national and European policy makers to **ensure that people with Spina Bifida and Hydrocephalus receive adequate health care and all the support they need to continue to live longer and better quality lives.** It also highlighted the importance of accessibility of the professional, multi-disciplinary care and support. It is imperative that policy makers take urgent action to combat the problems faced by people with Spina Bifida and Hydrocephalus as they age so that they enjoy older years in the same manner as other people.

Due to improved medical care, it is predicted that the number of elderly people with Spina Bifida and Hydrocephalus will rise over the next few decades. Taking action now would ensure that these people have the care and support they need to lead healthy and active lives into old age. On the contrary, ignoring this fact could have a severe economic and social impact.

The position paper was presented by Shine CEO and IF board member, Mrs Jackie Bland, in a Capacity Building workshop entitled: Adults and now? The workshop took place in the European Parliament in Strasbourg as part of events celebrating the World Spina Bifida & Hydrocephalus Day.

## International Day of Persons with Disabilities

**December 3** // The theme of the International Day of Persons with Disabilities in 2012 was: **Removing barriers to create an inclusive and accessible society for all.** To honour this special day, IF organised a photo exhibition at the European Commission entitled “Unfold their Potential - (Y)our return on investment”. The photographs gathered from IF members illustrate the lives of people with Spina Bifida and Hydrocephalus. Visitors were also informed about the IF Position Paper on Ageing with Spina Bifida and Hydrocephalus, which focuses on the urgent need to address the issues of adults living with these conditions. Persons with disabilities, “the world’s largest minority”, often face barriers to fully participate in all aspects of society. Barriers can take a variety of forms (i.e. those related to the physical environment or accessibility of information and communications technology) resulting in societal attitudes or discrimination. In consequence, persons with disabilities do not have equal access to society or services, including education, employment, health care, transportation, political participation or justice.

(Y)OUR  
RETURN ON  
INVESTMENT

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AGEING WITH SPINA BIFIDA  
AND HYDROCEPHALUS

## 2012 The European Year for Active Ageing and Solidarity between Generations

The year 2012 was aimed at raising awareness about the contribution that older people make to society and highlight the challenges they may face. IF joined the EY2012 coalition composed of more than 50 European organisations who took the European Year as an opportunity to address age discrimination and demographic change in a way that is fair and sustainable for all ages. **The Year promoted active ageing in 3 areas: employment, participation in society and independent living.**

It searched for innovative solutions to economic and social challenges facing the ageing European population. It also helped empower older people to stay in good physical and mental health and contribute more actively to the labour market and to their communities.

IF participated in the official closing conference of the EY2012 “From Visions to Actions” organised by the Cyprus EU Presidency in Nicosia. This event brought together high-level EU and national policy makers, civil society organisations and other stakeholders to celebrate the achievements of the year and to announce follow-up activities to ensure a lasting impact of the Year. Demetris Christofias, President of Cyprus, and László Andor, European Commissioner for Employment, Social Affairs and Inclusion, opened the conference.



# INTERNATIONAL SOLIDARITY

The winning strategy to achieve IF's goals requires developing solid partnerships around the globe.

## IF visit to China

**January 25** // IF president Pierre Mertens was invited by Spina China to visit the organisation and had several productive meetings with different stakeholders. The aim of the visit was to get a better understanding of the situation of children, families and adults with Spina Bifida and Hydrocephalus in China. FFI estimates the yearly cases of Spina Bifida in China at around 25000.

During this visit, Spina China organised a well-attended online conference, home visits and the awareness meeting in Chengdu. Spina China has 3000 members, mainly adults with Spina Bifida. Pierre Mertens initiated **IF's programme for continence management** and developed action plans to be implemented in China. IF looks into possibilities to empower and support Spina China.



## Plans for new Spina Bifida centre in Sudan

After several years of lobbying, the Spina Bifida Federal Association (SBFA), the Sudanese parent association, has successfully agreed with the Soba Teaching Hospital in Khartoum to establish the **Professor Ibrahim Abdul Aziz Centre for Children with Spina Bifida**. This centre is the first of its kind in Sudan and will greatly improve the treatment of children with SB. The SBFA is an IF member since 2010. With no established medical and lifelong care available in Sudan, the SBFA has been the only source of coordinated support for the children and their families in the Khartoum region. Thanks to their large network of doctors, surgeons, rehabilitation staff and other organisations, they have managed to ensure the minimal support needed.

## ETV programme in Tanzania

**April 2** // Dr. Hamisi Shabani from Muhimbili Orthopaedic Institute (MOI) performed the **40th successful ETV operation on a patient with Hydrocephalus**. MOI is the first governmental hospital in Tanzania that collaborates with IF in treating Hydrocephalus.

Dr. Hamisi Shabani was trained in ETV at CURE Hydrocephalus Surgeon Training Program, in CURE Children's Hospital in Mbale. CH Surgeon Training Programme was set up through a partnership between IF, CURE International and the Karl Storz Company. It was designed to utilize the expertise derived from continuing research undergone by CURE International Children's Hospital of Uganda (CURE Uganda) and its sister facilities, including CURE Zambia. The CURE Children's Hospital of Uganda has become the referral hospital for Spina Bifida and Hydrocephalus in Uganda. It has become the expert on alternative surgery of Hydrocephalus with ETV, making a natural bypass to drain the fluid in the head through endoscopic surgery.

## **Pierre Mertens received Spanish Solidarity Award**

Antonio Menchaca de la Bodega's Foundation, through a public call, awards people and entities well known in their daily life because of their solidarity effort. The Solidarity Award in 2012 was awarded to IF president, Mr. Pierre Mertens for his **longstanding commitment and tireless efforts to improve the lives of people with Spina Bifida and Hydrocephalus**, both in the North and in the South. Pierre received a bronze statue and a certificate as acknowledgment for his work. Inés Orella, president of La Asociación Bizkaia Elkarte de Espina Bífida e Hidrocefalia (ASEBI) accepted the award and expressed thanks on Pierre's behalf. The laureat emphasized how living differently does not necessary need to be a burden and how the experiences with his daughter Lies coloured his life. Her death inspired him to initiate the IF projects for children with Spina Bifida and Hydrocephalus in developing countries. Until now, 35 000 African children received the care they are entitled to.

## **Interdisciplinary care for children with Spina Bifida and Hydrocephalus in East and Southern Africa**

An article written by IF president Pierre Mertens and Femke Bannink (Child-Help/AVSI) has been published by the **Journal of Medicine and the Person**. They described IF's journey to improve care for children with Spina Bifida in East and Southern Africa through collaboration with local hospitals and community-based rehabilitation programs. A review of the various components of the programme highlighted successes and challenges of the past 20 years.

**Active parent involvement in care and an interdisciplinary approach are crucial for a successful lifelong care programme**, as well as engaging patients as partners in the development of understandable information for other patients. The IF programme shows how a cost-saving approach is feasible and does not need to imply a decrease in quality of care.

IF started working in East Africa in 1992. The IF programme then consisted of training co-workers of the Liliane Foundation, a Dutch NGO working for children with disabilities in Africa. Over the years, the programme expanded to 6 East African countries (Sudan, Kenya, Uganda, Tanzania, Zambia, and Malawi) and 20 local and international partners. IF aims to personalize the treatment of children with Spina Bifida and Hydrocephalus, avoiding unnecessary expensive and time-consuming treatment. This can only be possible through participation of parents, communities and devoted health care providers.



## Progress in Spina Bifida and Hydrocephalus treatment in Africa

Thanks to the increased cooperation between **BethanyKids at Kijabe Hospital in Kenya** and stakeholders in Ethiopia and Somaliland, the treatment and care of children born with Spina Bifida and/or Hydrocephalus has started to improve. In Ethiopia a nurse from the Myungsung Christian Medical Center (MCM) has received training and is now teaching mothers how to do a bladder evaluation. In Somaliland, the Edna Adan Maternity Hospital is offering surgery for children with Spina Bifida and/or Hydrocephalus. All surgical procedures are done under the supervision of a general surgeon doctor Deeqa Cumar, who has been trained in shunt surgery. She also does bladder evaluations and teaches mothers how to do this procedure themselves.

There are no neurosurgeons in Somaliland and Spina Bifida closure and shunt surgeries have never been performed there before 2007. Consistent shunting has occurred within Somaliland only since 2011. The next step in both Ethiopia and Somaliland is to organise proper follow-up care and better educate families about Spina Bifida and Hydrocephalus.



## International Solidarity in numbers

IF is one of the key players in facilitating the proper care and treatment of Spina Bifida and Hydrocephalus in developing countries. The actual impact on the

everyday lives of people with SB/H is made by the successful work of many doctors, nurses, and volunteers who devoted their time and shared their knowledge. The real value of their contribution is vast reaching and cannot be fully measured, however below we present some figures showing the success of our international programmes in developing countries in 2012.





# NETWORK DEVELOPMENT

Networking on a daily basis in order to remain visible and influential for Spina Bifida and/or Hydrocephalus. Expanding the IF network so that people with SB/H are represented worldwide by strong local organisations.

## Rare Disease Day 2012

**February 29** // 2012 marked the fifth International Rare Disease Day. On this day hundreds of patient organisations from more than 50 countries worldwide organised awareness-raising activities converging around the slogan “**Rare but strong together**”. IF participated in the event organised by the European Organisation for Rare Diseases (EURORDIS) at Centre de Presse Internationale.

## Finding Our Way: IF's 23rd International Conference

**June 15-16** // IF's 23rd International conference took place in Stockholm and was the largest gathering dedicated to Spina Bifida and Hydrocephalus to date in Sweden. Over 320 participants from 25 different countries from Europe, USA, Canada, Russia, Argentina and Kenya gathered for two days to share the latest information related to Spina Bifida and Hydrocephalus. The conference was organised around lectures, creative and thematic workshops and networking activities. Subject matters and challenges related to Spina Bifida and Hydrocephalus were covered from different perspectives.

### Annual meeting in brief:

- IF president Pierre Mertens stressed that **people with Spina Bifida and Hydrocephalus and people with disabilities in general should not have to pay the price for any economic or financial crisis**. He emphasized the importance of solidarity between people, associations and countries to guarantee the execution of the rights of people with Spina Bifida and Hydrocephalus.
- Pierre Mertens, Lieven Bauwens (IF Secretary General) and Jackie Bland (Co-opted Board member and IF

treasurer) presented the activity and financial reports for 2011 that were adopted by the general assembly.

- Three applications for IF membership were approved: IF network is now officially enlarged by Spina Bifida Association Madrid, Spina Bifida and Hydrocephalus Bulgaria, and Fundación Mónica Uribe Por Amor from Colombia.
- Catriona Clarck, IF volunteer from Scotland, presented the position paper: Overcoming the challenges of ageing faced by people with Spina Bifida and Hydrocephalus.
- The General Assembly elected David Diaz Garcia from Spina Bifida Association Madrid and SHINE's CEO, Jackie Bland from the UK, as new IF board members.
- Dr. Margo Whiteford, Chair of the Scottish Spina Bifida organisation was elected as the next president of IF and shall be officially announced at the next Annual Conference and General Meeting that will take place in June 2013 in Izmir, Turkey.

IF addresses a special thanks to the organising committee from RBU for their tremendous work and dedication for preparing the annual conference. All the presentations are available on the IF website: [www.ifglobal.org](http://www.ifglobal.org)

## IF workshop on Structural Funds

Finding funds remain one of the main challenges faced by patient organisations in general. The financial crisis and the cuts in national budgets have put most patient organisations in a difficult situation to keep up with the organisational costs and to cover ongoing activities.

IF organised a workshop on the **European Structural Funding for Disabled People Organisations** designed for its European members. This workshop was the fruit

of the internal survey conducted by IF in 2011 which results concluded that most member associations needed training and capacity building on fundraising. The workshop gave a practical overview of the European Structural Funds, the budget allocated and the application procedure. The presentations gave the participants guidance on how to successfully apply for such funds.

Marianne Öberg-Håkansson, national coordinator for the European Social Fund in Sweden presented the ESF and how it works in Sweden. Stefania Pirani from IF Secretariat in Brussels explained how to apply for a project with a concrete example taken from Ireland. Lennart Asp, project manager with a background in special education and Margaret Fintling who works as a social consultant at the Employment Service in Örebro, presented the project "Job in sight" granted by the ESF in Sweden. Simona Giarratano, Social Policy Officer at European Disability Forum gave an overview about the Structural Funds after 2013 and the next generation of funds from 2014 to 2020.

## IF Award 2012

The 2012 IF Award was awarded to Dr. Sven Mattsson and his wife Dr. Gunilla Glad Mattsson from Sweden for their commitment and dedication to the Spina Bifida and Hydrocephalus community.

**Dr. Sven Mattsson, MD, PhD** is an associate professor and a neuro-paediatrician at the department of paediatrics at the University Hospital of Linköping. He is a Honourable Member of the Executive Committee of Society for Research into Spina Bifida and Hydrocephalus in the UK.

**Dr. Gunilla Glad Mattsson, Med, PhD** is an urotherapist and a senior lecturer at the department of paediatrics at the University Hospital of Linköping. She is a mother of an adult with Spina Bifida and active

researcher in assessment and treatment of the neurogenic bladder dysfunction of children and adolescents with Spina Bifida. Both Sven and Gunilla are members of the Swedish national working group for registration and follow-up program for individuals with Spina Bifida. Their commitment in improving the lives of people with Spina Bifida has led them to get involved in Pristina, Sarajevo and Montenegro and they are planning to take part in activities in Africa.

## IF workshop: Adults, and now?

**October 23** // IF organised a Capacity Building Workshop for Disabled People Organisations (DPOs) of persons with Spina Bifida and Hydrocephalus. The aim was to **increase the capacity of DPOs to advocate for the rights of adults with Spina Bifida and Hydrocephalus.**

Dima Yared, Human Rights Officer at United Nations Office for Human Rights, Regional Office for Europe, presented examples on how to use the UNCRPD to advocate for and promote the rights to work of people with disabilities.

Martin Künemund presented the project "We empower Us-bh" to share knowledge and good practices to improve job opportunities for people with Spina Bifida and Hydrocephalus.

Jackie Bland, Chief Executive of Shine, gave a presentation of the IF position paper on aging of people with Spina Bifida and Hydrocephalus and explained how to use it to advocate at national level.

MEP Diane Dodds and MEP Catherine Stihler presented insights into the work of advocacy and networking at the European Parliament for the rights of people with disabilities and engaged in discussions with the participants.



## **Ben Warf receives MacArthur Foundation Fellowship**

IF's medical advisor Dr. Ben Warf has been named a 2012 MacArthur Foundation Fellow for his **revolutionizing work in the treatment of very young children with Hydrocephalus**. The MacArthur Fellowship is an award to support people, not projects, as an investment in their originality, insight, and potential. Ben Warf was rewarded for advancing standards and access to health care in both the developed and poorest regions of the world. He designed a training program and network for neurosurgeons throughout Africa, Asia, and the Middle East, increasing exponentially the number of children who can now be treated by using modern endoscopic techniques.

Dr. Ben Warf is IF medical advisor and partner for multitudes of projects in Africa. He has received the IF award in 2005 in Minneapolis and has been actively involved in IF's international conferences. From 2000 to 2006, he was a medical director and chief of surgery at CURE Children's Hospital in Uganda, and in 2010 he joined the faculty of Harvard Medical School. He is currently an associate professor of surgery and director of the Neonatal and Congenital Anomaly Neurosurgery Program at Boston Children's Hospital.

## **3rd European Parliament of Persons with Disabilities**

**December 5** // IF took part in a gathering of more than 450 delegates from organisations representing persons with disabilities (DPOs) from all over Europe. The aim was to meet with European Parliament leaders, MEPs and EU decision-makers in order to discuss **how Europe can ensure the protection of the rights of persons with disabilities in this time of crisis**.

The event was structured similarly to a usual plenary session of the European Parliament by using the same speaking rules.

Delegates from DPOs voted a resolution calling on the European institutions and consultative bodies, the EU member states, the social partners, organised civil society, and other stakeholders to take appropriate steps towards the implementation of the rights of persons with disabilities in Europe.



# FINANCIAL RESULT IN 2012

Achieving our objectives requires efficient management of resources and effective fundraising.

## Statement of the auditor

Report of the auditor on the financial statements for the year ended 31.12.2012 addressed to the general meeting of “International Federation for Spina Bifida and Hydrocephalus” (Cellebroerstraat 16-1000 Brussels).

In accordance with the assignment by the board of directors, we report to you on the performance of the audit mandate which has been entrusted to us. We have audited the financial statements for the year ended 31.12.2012, prepared under the responsibility of the board of directors of the federation, which show a balance sheet total of € 804.767,08 and a profit for the year of €5.497,59.

modify our audit opinion on the financial statements:

- Without prejudice to formal aspects of minor importance, the accounting records were maintained in accordance with the legal and regulatory requirements applicable in Belgium.
- Otherwise, we do not have to report to you any transactions undertaken or decisions made in violation of the bylaws of the articles of the Law on Non-Profit-Organisations.

Lennik, March 20th 2013

Roger De Nul  
Auditor

## Unqualified audit opinion on the financial statements

Our audit was planned and performed to obtain reasonable assurance about whether the financial statements are free of material misstatement. Federation officials have responded clearly to our request for explanations and information.

On a test basis, we have examined the justification for the amounts included in the annual accounts.

We have assessed the accounting policies, the significant accounting estimates made by the federation and the overall financial statement presentation. We believe that our audit provides a reasonable basis for our opinion. In our opinion, taking into account the legal and regulatory requirements applicable in Belgium, the financial statements for the year ended 31.12.2012 give a true and fair view of the federations' assets, liabilities, financial position, and results of operations.

Additional certifications and information  
We supplement our report with the following certifications and information which do not



## Balance sheet on 31 December 2012

<b>Assets</b>	<b>31-dec-12</b>	<b>31-dec-11</b>
<b>TANGIBLE ASSETS</b>	<b>3.548,00</b>	<b>3.876,33</b>
IT & office supplies	8.980,80	11.965,74
Depreciations IT & office supplies	-7.394,71	-10.766,89
Office furniture	3.577,83	3.577,83
Depreciations office furniture	-2.146,71	-1.431,14
Cautions	530,79	530,79
<b>AMOUNTS RECEIVABLE</b>	<b>91.950,41</b>	<b>82.728,06</b>
Customors	57.008,50	29.298,03
Dubious debtors	6.910,07	0,00
Depreciations customors	-6.910,07	-7.043,07
Advances	266,38	0,00
Subsidies to receive	30.000,08	47.763,65
Divers to receive	0,00	737,78
IF Child Help current account	4.675,45	11.971,67
<b>BANK &amp; CASH ACCOUNTS</b>	<b>709.137,09</b>	<b>233.750,04</b>
KBC - long term accounts	20.000,00	20.000,00
KBC - accounts	10.760,39	3.055,56
KBC - accounts saving	678.255,76	210.573,54
Pay pal	120,94	120,94
<b>TRANSIT ACCOUNTS</b>	<b>131,58</b>	<b>5.406,20</b>
Costs for next year	131,58	5.406,20
<b>Total assets</b>	<b>804.767,08</b>	<b>325.760,63</b>

<b>Liabilities</b>	<b>31-dec-12</b>	<b>31-dec-11</b>
<b>RESERVES</b>	<b>253.845,29</b>	<b>248.347,70</b>
Funds of IF	248.347,70	260.282,63
Profit-los bookyear	5.497,59	-11.934,93
<b>AMOUNTS PAYABLE</b>	<b>80.082,08</b>	<b>77.412,93</b>
Suppliers	5.785,00	16.491,83
Taxes to be paid	3.287,27	2.380,18
Social charges to be paid	1.734,69	1.420,85
Salary's to be paid	5.121,17	1.344,15
Provision holiday fee	20.245,08	21.155,19
Projects current accounts	43.908,87	33.459,68
Divers to pay	0,00	1.161,05
<b>TRANSIT ACCOUNTS</b>	<b>470.839,71</b>	<b>0,00</b>
Profits for next year	470.839,71	0,00
<b>Total liabilities</b>	<b>804.767,08</b>	<b>325.760,63</b>

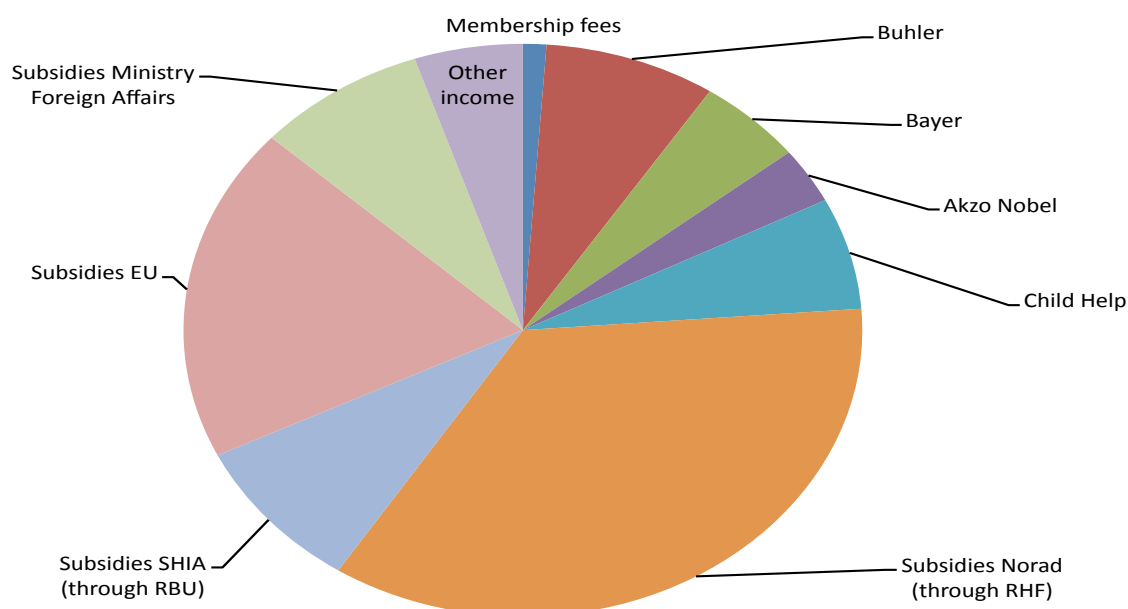
## Profit and loss 2012

<b>General Costs</b>	<b>495.342,48 €</b>
Housing costs	21.071,38 €
Office supplies	5.131,86 €
Communication costs	4.527,92 €
Shipping costs	2.290,66 €
Membership	1.275,00 €
Payroll costs	6.548,21 €
Bookkeeping	3.742,63 €
Audit	2.147,75 €
External evaluation	1.998,00 €
Insurance	1.323,14 €
Other fees	2.224,15 €
Publications	4.577,64 €
<b>Exhibition and Publications</b>	
World Spina Bifida and Hydrocephalus Day	19.669,60 €
Consultant - China	6.000,00 €
Consultant - Flour Fortification	10.410,00 €
Travel	61.752,09 €
Accommodation and subsistence	25.949,87 €
Conferences - Workshops	77.433,97 €
Medical material to projects	46.811,42 €
Salaries in projects	90.188,14 €
Training in projects	23.413,08 €
Treatment and rehabilitation in projects	14.585,50 €
Parent meetings in projects	29.368,67 €
Sensitization and advocacy in projects	7.365,67 €
Prevention activities in projects	9.043,85 €
Research in projects	3.682,74 €
Administration in projects	9.279,87 €
Other costs	3.529,67 €
<b>Salary Costs</b>	<b>285.133,45 €</b>
Depreciations	3.794,73 €
Financial Costs	1.511,54 €
Exceptional Costs	911,00 €
<b>TOTAL Costs</b>	<b>786.693,20 €</b>

<b>General Income</b>	<b>751.260,10 €</b>
Membership fees	8.825,00 €
Contribution Bühler	64.770,29 €
Contribution Bayer	40.000,00 €
Contribution Akzo Nobel	25.000,00 €
Contribution Child Help	50.005,73 €
Subsidies Norad (through RHF)	280.000,00 €
Subsidies SHIA (through RBU)	68.502,82 €
Subsidies EU	150.000,00 €
Subsidies Ministry Foreign Affairs	64.156,26 €
<b>Diverse recuperation</b>	<b>37.643,57 €</b>
Financial Income	2.962,96 €
Exceptional Income	324,16 €
<b>TOTAL Income</b>	<b>792.190,79 €</b>

**RESULT 5.497,59 €**

### IF Income FY 2012



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The seven-year Programme targets all stakeholders who can help shape the development of appropriate and effective employment and social legislation and policies, across the EU-27, EFTA-EEA and EU candidate and pre-candidate countries.

For more information see: <http://ec.europa.eu/progress>

The information contained in this publication does not necessarily reflect the position or opinion of the European Commission.



European Commission  
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