



# Annual report 2011

## Opening doors



INTERNATIONAL FEDERATION  
FOR SPINA BIFIDA AND HYDROCEPHALUS

IF ivzw  
International Federation for Spina Bifida and Hydrocephalus  
Consultative status special category, Economic and Social Council of the United Nations  
Participatory Status, Council of Europe

# Annual Report 2011

Opening doors

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# Introduction

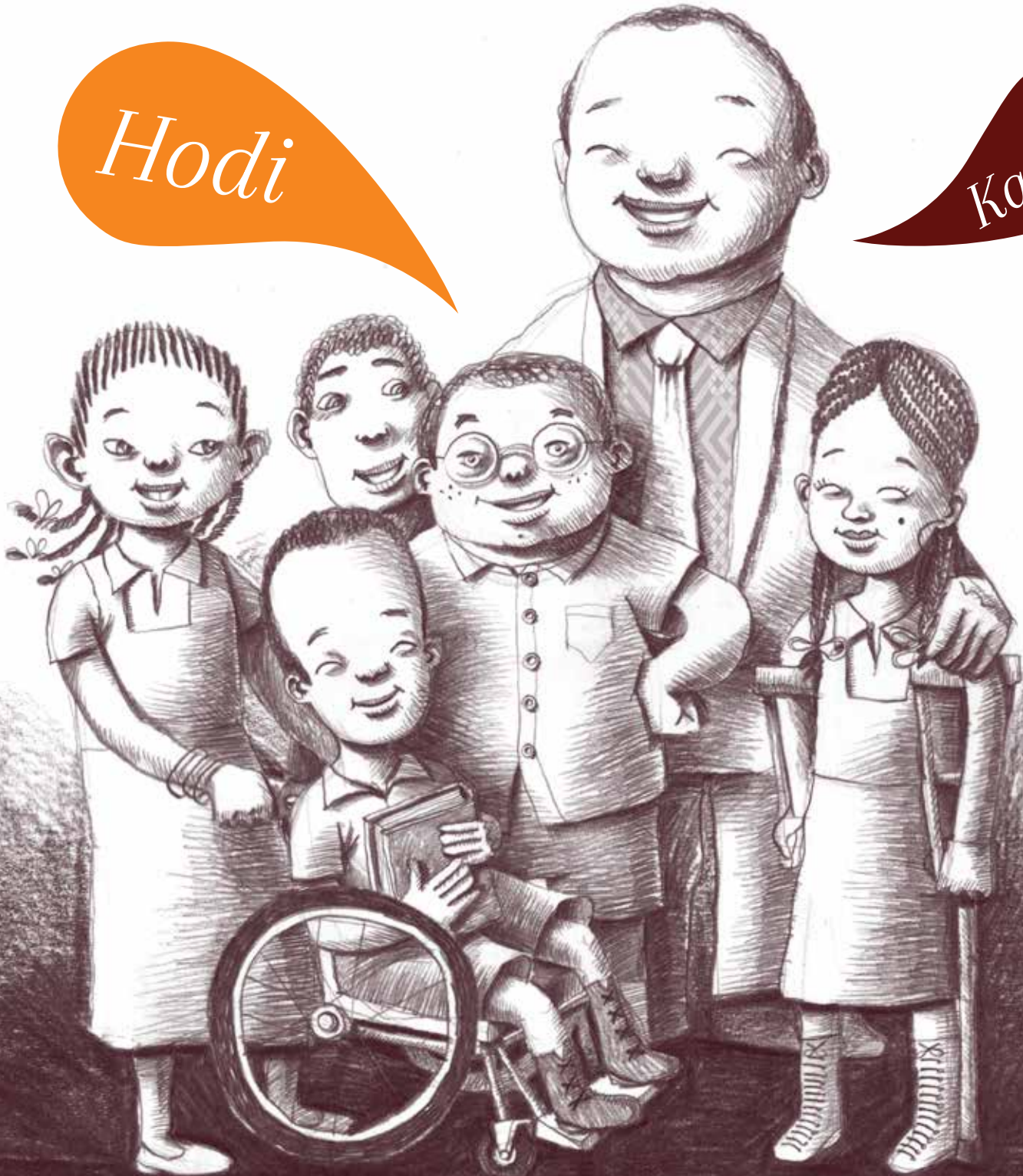
## Opening doors

Dear friend of IF,

Hodi was the theme of our East African workshop on inclusive education in Nairobi. *“Hodi”* is Swahili and means *“Can I come in?”*. *“Karibu”*, the answer, means *“Welcome”*.

*Hodi*

*Karibu*



Children and adults with Spina Bifida & Hydrocephalus (SB&H) often face closed doors caused by negative stereotypes of their disability or by an inaccessible society. That is why our Guatemalan member association chose **'Opening Doors'** as the theme for our 2011 International Conference. Doors are a national symbol in Guatemala. The conference opened successfully the IF door to all Latin American countries. During the closing ceremony the IF Award this year was presented to World Pediatric Project, an organisation working towards similar goals in Central America and the Caribbean as IF is doing in Africa to better the lives of children born with SB&H.

The UN Convention for the Right of persons with a disability (UNCRPD) underlines that all of society has to open their doors to us too. It became an important tool for inclusion.

To be part of the world we need to fight negative stereotypes of our disabilities. If we want governments and policymakers to invest in good care we need to show them a positive but realistic image of our lives with SB&H.

In our second Neural Tube Defect report 'Act against Europe's most common birth defects' we combined Neural Tube Defect prevention with a clear statement on the value of our lives. IF and its members took the lead in primary prevention, from Vietnam through China to Europe, America and Africa.

IF's International Solidarity Program started in 1993 and has already saved thousands of children, primarily in Africa. Proudly, we are welcoming some kids from the initial program as staff members in our projects, while others are attending university.

CURE, our partner in Mbale, celebrated its 10th anniversary in 2011. I witnessed children of all ages dancing for the audience, at the same time thinking about all the new children arriving in increasing numbers every year. Our partners are already overloaded.

The African workshop 'Sailing Off' in Kampala, Uganda, introduced SHIP (Spina Bifida & Hydrocephalus Interdisciplinary Program) promoting an interdisciplinary approach where all stakeholders work together in the lifelong care of our children. Access to lifesaving treatment is realised in the IF projects, but unfortunately in too many countries around the world children have no access to care at all. Each year these children are surviving or dying in inhumane conditions.

National associations for Spina Bifida and Hydrocephalus are the best guarantee for good care in a country. Therefore IF makes many efforts to stimulate the establishment of these groups in countries where they do not exist. We participated in workshops in the Czech republic and Bulgaria, which may be the start of new foundations. This year, we welcomed new member organisations from Australia, Poland and Greece (back) into the IF family.

Access to care became one of IF's main focal points. It is a Human Right specified in the UNCRPD to have access to all available lifesaving treatment. Both for unborn and newborn children, and for children and adults with SB&H of all ages. With a growing number of adults and aging people with Spina Bifida, coordinated adult care is urgently needed and therefore we organized a European workshop on this topic.

You can read about all this and much more in this annual report 2011. Sustaining expanding projects and meeting growing demands in a year of financial crisis is a huge challenge. We depend on our partners and donors and on many volunteers like you and me to make this happen. With your help we can open doors.

**Pierre Mertens**

*President IF*

# What we achieved in 2011

The mission of IF is to improve the quality of life of people with Spina Bifida and Hydrocephalus worldwide and to decrease the prevalence of Spina Bifida and Hydrocephalus by means of primary prevention.

## Achievement 2011

The mission of IF is to improve the quality of life of people with Spina Bifida and Hydrocephalus worldwide and to decrease the prevalence of Spina Bifida and Hydrocephalus by means of primary prevention. To achieve its mission, IF tries to put Spina Bifida and Hydrocephalus higher on the (political) priority list.

IF reaches even more people through its website, publications, newsletters, events, partnerships... (→ see pages 19, 23, ...)



IF organised several successful conferences and workshops (Guatemala City, Brussels, Leuven, Sofia, Kampala, Dar Es Salaam) (→ see pages 11, 13, 14, 21, ...)

IF's network keeps expanding with more members (Australia, Poland, Greece). IF is engaged in more partnerships (FFI, IDDC, EURORDIS). (→ see pages 12, 24, 25, ...)



In its International Solidarity Programme, IF has expanded its reach and is now touching more lives directly (see pages 20,21, ...)

# The International Federation for Spina Bifida and Hydrocephalus

## Board of Directors

Mr. Pierre Mertens - president, Belgium  
Mrs. Eli Skattebu - vice-president, Norway  
Mr. Teije Dijk - treasurer, the Netherlands (until June 2011)  
Mr. Douglas Sorocco - USA  
Dr. Erwin Calgua - Guatemala  
Mrs. Eva Toft - Sweden  
Mr. Luís Quaresma - Portugal  
Mrs. Thelma Cloake - Ireland  
Dr. Margo Whiteford - Scotland (UK)  
Mrs. Jackie Bland - UK (from June 2011)  
Mrs. Elena Monzón de Zappoli - Argentina (from June 2011)

The board met in person in March (Izmir, Turkey),  
June (Antigua, Guatemala) and November (Brussels, Belgium) 2011

### Board meeting

#### November 2011, Brussels:

Mr. Douglas Sorocco  
Mrs. Elena Monzón de Zappoli  
Mrs. Thelma Cloake  
Dr. Margo Whiteford  
Mr. Pierre Mertens  
Mrs. Eli Skattebu  
Mrs. Jackie Bland  
Mr. Lieven Bauwens  
Mrs. Eva Toft

### Not pictured:

Mr. Luís Quaresma  
Dr. Erwin Calgua  
Mr. Teije Dijk







## Staff

### Brussels office

Mr. Lieven Bauwens - Secretary General  
Mrs. Katalijne Van Diest - Coordinator Development Cooperation  
Mrs. Stefania Pirani - Coordinator European Projects  
Mrs. Renée Jopp - Information officer  
Mr. Badr Mouhcine - Communications officer

### Kampala office

Mrs. Rebecca Nakitto Sagabo - Administrative assistant, East-Africa  
Mrs. Femke Bannink - coordinator

### IF volunteers

Mrs. Vanessa Eyeghe  
Mrs. Brigid Glennon  
Mrs. Greta Van Seghbroeck  
Mr. Eric Holdtgrefe  
Mrs. Viviane Lepingle  
Mr. Zjuul Devens

## 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. Lieven Bauwens represents IF in the Executive Management Team of the Four 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  
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  
Dr. Anna Verster - senior consultant Flour Fortification Initiative  
Prof. Dr. Patrick De Vlieger - anthropology and disability  
Prof. Benjamin C. Warf - medical consultant, paediatric neurosurgeon, ABNS, ABPNS  
Mrs. Kordelia Fischer-Borchert - consultant community-based rehabilitation

# Priority area 1 Prevention

## NTD report “Act against Europe’s most common birth defects: one year on – Defining Neural Tube Defect prevention strategies in Europe”

In June 2011 IF and Bayer HealthCare Pharmaceuticals launched the joint report “Act against Europe’s most common birth defects: one year on - Defining Neural Tube Defect prevention strategies in Europe” under the auspices of the Hungarian Presidency of the EU. The report was developed in collaboration with EASPD, EFCNI, EURORDIS and MediClara. Both Bayer HealthCare Pharmaceuticals and MediClara are corporate sponsors of the report. This 2nd report followed the first joint report on Neural Tube Defects “Act against Europe’s most common birth defects - The right advice at the right time can reduce Neural Tube Defects now”, published in January 2010.

Many high-level speakers attended and committed to very concrete and positive next steps. Ms Paula Duarte Gaspar, Member of Cabinet of John Dallì, Commissioner for Health and Consumer Policy, stressed in the opening remarks the importance of supporting the visibility

of the NTD prevention cause. She described the report as an “excellent testimony” to the situation “making an important contribution to policy, bridging gaps, providing information and connecting experts”. MEP Edite Estrela closed the event with the following statement: “Join our efforts to ensure that health inequalities do not start before birth”.

Mr. Mertens, IF president, called on the EU to ensure NTD prevention is included in related EU policy, continue funding European registries, coordinate action and ensure exchange of best practices, and explore new methods to raise folate levels of women of childbearing age including food fortification and supplementation strategies.



Mr Lars Jaensson - Bayer Healthcare | Ms Silke Mader - European Foundation for the Care of Newborn Infants (EFCNI)  
Mr Yann Le Cam - European Organisation for Rare Diseases (EURORDIS) | Ms Paula Duarte Gaspar - Member of Cabinet of John Dallì, European Commission | Mr Pierre Mertens - International Federation for Spina Bifida and Hydrocephalus (IF) | Dr Denhard de Smit - MediClara  
Ms Edite Estrela - MEP (S&D, Portugal) | Ms Rhonda Curran - EUROCAT

## EU Executive Workshop “Making our network stronger - Raising aware- ness on prevention”

IF promotes awareness on prevention and the importance of Folic Acid for women of childbearing age to reduce the risk of NTD-affected pregnancies. In June 2011, IF has brought together representatives of IF member organisations from all over Europe to gather in Brussels in the framework of its EU Executive Workshop entitled “Making our network stronger – Raising awareness on prevention”. IF invited a selection of speakers from within its own organisation and from its network to help European IF members raise awareness on prevention in their respective countries.

The workshop was presented in four activities promoting interactivity between IF members and IF network of experts. The first part consisted of contributions of IF members. Examples of successful campaigns from the UK, Norway and Italy were shared with all participants. Secondly, practical guidelines on how to prepare national campaigns and how to effectively use social media were provided. Third, information on flour fortification with folic acid and its importance in preventing NTDs was presented by Robert Baldwin, Centers of Disease Control and Prevention and Flour Fortification Initiative representative. The workshop was concluded with working groups’ activity where each group discussed and presented ideas and proposals for future national campaigns on prevention.

- Prevention campaign Italy  
“I cannot consider a life without folic acid” presented by Mario Orgiana and Christina Dieci
- Prevention campaign UK  
“Go Folic!” presented by Laura Read
- Prevention campaign Norway  
“Rethink Folate” presented by Eli Skattebu and Kim Hannisdal



## International Mühlenchemie Symposium 'Future of Flour'

IF's Secretary General, Mr. Lieven Bauwens, presented "The economic impact of folate fortification" at the 4th International Mühlenchemie Symposium "Future of Flour". The event took place in Hamburg, September 8-9, 2011, and was attended by more than 300 participants. For two days in Hamburg, everything revolved around scientific findings, economic trends and technical innovations in the milling industry. The involvement of the representative organisation of persons with Spina Bifida and Hydrocephalus is new in this environment.

The symposium gave special attention to the African continent. Experts from Nigeria, Tanzania and Algeria described the current position of the milling industry in Africa and gave an overview of expected future challenges. Mr. Bauwens was one of 28 internationally renowned speakers from 18 countries.

## EURORDIS

IF partnered with the European Association for Rare Diseases (EURORDIS) in organising a brainstorming and policy development workshop on prevention of Neural Tube Defects in Europe. Prevention of disabilities and rare diseases should be in every National Action Plan on Rare Diseases. At this moment, this is not yet the case, but IF's member organisations are working locally to make this a reality.

## 15-Year Celebration: Fortify for life

In 2011 the Flour Fortification Initiative (FFI) celebrated the progress made in helping children get a healthy start in life and encouraging fortification to become standard milling practice globally.

In just 15 years, adding folic acid to flour has become a life-altering business practice resulting in the prevention of more than 22,000 serious birth defects every year. That is an average of 60 healthy babies a day born worldwide without these birth defects because flour is fortified, but this is only 9% of the birth defects that could be prevented if all women of childbearing age consumed enough folic acid. Oman was the first country to reach national scale fortification, and now, in 2011, 54 countries require mandatory addition of folic acid to their flour.





## Smarter Futures

In a partnership with the Flour Fortification Initiative, Akzo Nobel NV and Helen Keller International, IF has been working since 2009 on the improvement of the capacity of African millers and African government officials to make fortifying flour a standard practise in Africa. The project, partly funded by the Dutch government, is called "Smarter Futures". It involves setting national or regional standards, assuring or controlling the quality of the micronutrient mix in the flour and extensive advocacy.

4-8 April 2011, a workshop on Quality Control and Quality Assurance took place with the a lectures of Pierre Mertens, president of IF and Dr Hamisi Kimaro Shabani, neurosurgeon at the Muhimbili Orthopedic Institute (MOI). The involvement of the Association for Spina Bifida and Hydrocephalus of Tanzania (ASBAHT) has proven to be crucial in the advocacy for the prevention of birth defects by the fortification of cereal grains.

The project also focussed on monitoring progress in the countries (Monitoring and Surveillance) and country visits by the different partners.



## Launch of the World Report on Disability

On June 9<sup>th</sup>, 2011, the World Health Organization (WHO) and the World Bank have launched the World report on disability at the United Nations Building in New York. The World report suggests that more than a billion people in the world today experience disability. People with disabilities have generally poorer health, lower education achievements, fewer economic opportunities and higher rates of poverty than people without disabilities.

This is largely due to the lack of services available to them and the many obstacles they face in their everyday lives. The report provides the best available evidence about what works to overcome barriers to health care, rehabilitation, education, employment, and support services, and to create the environments which will enable people with disabilities to flourish.

IF was represented at this important launch by its medical advisor Prof. Dr. Benjamin Warf, Associate Professor of Surgery, Harvard Medical School, and David Morrissey, Executive Director of the United States International Council on Disabilities (USICD), who has Spina Bifida.



## United Nations Convention on the Rights of Persons with Disabilities.

The UNCRPD is the latest UN convention, adopted on 13 December 2006, and it is extremely important for the work of IF. More and more countries ratify and legislation is to be adopted at national level to comply with the convention's regulations. For IF, articles 6, 10 and 25 (protection of children with disabilities, inherent right to life and access to healthcare) are central to our advocacy. IF expects that the convention will ensure countries won't marginalise persons with disabilities. Governments ratifying the convention will be legally bound to respect all aspects of human rights of persons with disabilities.

[www.un.org/disabilities/convention/conventionfull.shtml](http://www.un.org/disabilities/convention/conventionfull.shtml)

## Conference on the rights of children with disabilities by Lumos in Bulgaria

### IF speaks about Spina Bifida and Hydrocephalus

On 24 November 2011, Lumos, supported by IF, organised a conference on the situation of children with SB&H in Bulgaria. Lumos has as main goal to stimulate deinstitutionalisation of children with a disability.

Adriana Tontsch from IF's Romanian member association reported their successful activities to have surgery early after diagnosis. Jan Jařab, regional representative of the UN High Commissioner for Human Rights, underlined that no care and surgery is not an option. The ministry of Health announced during the conference that shunts will be refunded for children in need and that a multidisciplinary team will be started in Varna.

## IF collaborates with EDF on Bio-Ethics

The European Disability Forum's (EDF) Board Meeting in Milan, Italy, focussed on the effects of the financial crisis on persons with disabilities (PWDs). Erik Olsen gave a historical background of the disability movement from segregation to inclusion. The financial crisis could mean a return to the past. For instance, the proposed financial cuts in Denmark affect directly the income of PWDs. Prof. G. Abba warned that in times of crisis discrimination rises. The crisis has an impact on the education and employment of PWDs. Returning to philanthropy is dangerous because it is based on voluntary actions and against the right of services. The UNCRPD has to be used to safeguard the needed funds to have full participation in society. The disability movements have to advocate on national and European level to transform disability rights into legislations and policies.

During its meeting the EDF board accepted a proposal submitted by IF and other European Disabled People Organizations to start an expert group on 'barriers to access health services for persons with disabilities'. The Expert Group will document and study how stereotypes on disability have an influence on the access to lifesaving treatment and in prenatal and postnatal counselling.

In 2009 IF published its Position Paper on the Groningen Protocol, which concluded that medical decision-making and counselling that is based on anticipated "quality of life" for an infant with impairments violates international human rights standards. It is important to study the effects of disability and stereotyping on a broader scale. The group will be formed by members of national councils and European NGO's. Candidates will be elected at the next General Meeting of EDF.

**IF advocated that Disabled Persons Organisations should be involved in the decision making process of making budget cuts.**



**IF, represented by Pierre Mertens and Lieven Bauwens, advocated for correct interdisciplinary care to prevent parents from abandoning their children in institutions without care.**

Pierre Mertens and Lieven Bauwens with members of the Bulgarian association for Spina Bifida and Hydrocephalus during the conference on the rights of children with disabilities.

## IF projects in developing countries

Children with a disability are not a priority in the developing world. For many years, IF has been working, together with its partners and experts, to translate the latest knowledge of the North into realistic and practical care for the South, and work locally to change the attitudes of governments, service providers and society in general.

While health care delivery and service delivery in general are poor in developing countries, the situation is even worse for services for disabilities, especially related to neurological conditions and severe impairments. There is a tendency to exclude persons with disabilities because of negative attitudes, stereotype thoughts, insufficient believe in their capacity and unsuitable facilities, physical and social barriers, amongst other challenges. Public institutions often lack strategies to ensure that the rights and needs of persons with disabilities are met.

The disastrous outcome of children left untreated or treated incorrectly contributes to the downwards spiral where negative outcomes leads to further loss of hope and believe in the future of children with SBH, by health care workers, parents and society in general. Where there is no hope and believe, health systems and governments stop looking for solutions to improve the care for children with SBH. Without realistic solutions, more children will become victims of a failing health system and end up with a poor diagnosis, confirming the image of negative outcome for children with SBH.



**Only when successful medical and lifelong care is provided, with positive outcomes as a result, people will start believing in the future of their children. This will gradually change the image of children with SBH and reduce the current stigmatization.**





IF has been able to develop, with the help of reliable local partners and INGOs, a comprehensive package for prevention, treatment and rehabilitation of children with Spina Bifida and Hydrocephalus in six African countries thanks to the following partners:

- Ryggmargsbrokk- og hydrocephalusforeningen (RHF Norway), supported by the Norwegian government (via NORAD through Atlas Alliance)
- Riksförbundet för Rörelsehindrade Barn och Ungdomar (RBU Sweden), supported by the Swedish government (via SHIA)
- Child Help Belgium, supported by over 10.000 individuals in Belgium

The goal of the work in developing countries is to reach a better life situation for people with Spina Bifida and Hydrocephalus through support of local based rehabilitation and lifelong care programs and the support of parent groups, through the following objectives:

- Improve the basic local conditions for the treatment and rehabilitation of children with Spina Bifida and Hydrocephalus by organising appropriate training on all levels
- Empowerment of groups of parents and people with Spina Bifida and Hydrocephalus
- Social inclusion of people with Spina Bifida and Hydrocephalus and increase the expertise on rehabilitation and inclusion matters
- Increase knowledge on the diagnosis through research
- Assist and support NGOs to provide good services to people with Spina Bifida and Hydrocephalus
- Research on the causes and incidence of Spina Bifida and Hydrocephalus
- Primary prevention

The official partners in the countries where IF works are:

- Uganda, Mbale: CURE Children's Hospital
- Uganda, Kampala: Katalamwa Cheshire Home
- Uganda, Mbarara: O.U.R.S. for People with Disabilities
- Tanzania, Moshi: CCBRT CBR Kilimanjaro in cooperation with KCMC
- Tanzania, Dar es Salaam: Association for Spina Bifida and Hydrocephalus Tanzania (ASBAHT)
- Tanzania, Arusha: Arusha Lutheran Medical Centre (ALMC)
- Tanzania, Zanzibar: Zanzibar Association for People with Developmental Disabilities (ZAPDD)
- Kenya, Kijabe: Bethany Kids at Kijabe Hospital
- Zambia, Lusaka: Beit CURE Hospital
- Malawi, Blantyre: Queen Elisabeth Central Hospital in cooperation with Beit CURE Hospital
- Sudan, Khartoum: the Spina Bifida Federal Association

Besides these official partners, IF has a wide network with international NGOs, NGOs in the South and other foundations, enabling us to reach and work for our target group: children and adults with Spina Bifida and/or Hydrocephalus. These partners include: CURE International, Liliane foundation, AVSI, Handicap International, Bethany Relief and Rehabilitation, and IDDC.

**Many hospitals, universities and other organisations, and individuals from all over the world have benefitted from the knowledge and information that is available within IF and its knowledge network.**

in 2011, IF has been able to supply cost-efficient shunts to partners in the following countries: Angola, Colombia, DR Congo, Ethiopia, Ivory Coast, Haiti, Honduras, Indonesia, Kenya, Liberia, Malawi, Nigeria, Rwanda, Sudan, Tanzania, Uganda, Zambia, Zimbabwe

## Community-based rehabilitation saves lives

In the districts of southeastern Uganda many children with Spina Bifida and Hydrocephalus (SBH) are referred to and treated at CURE Children's Hospital in Mbale. However, the long-term survival of these children and its important determinants are unknown.

IF's medical advisor Prof. Dr. Benjamin Warf, together with Dr. Wright and Dr. Kulkarni, studied the data of 140 children treated for SBH at CURE Uganda. Districts with active community-based rehabilitation programmes showed significantly higher survival rates for these children, approaching that for their unaffected peers. Adequate home and community support after discharge from the hospital appears essential to continued survival. CBR programmes are crucial for the survival of children treated for Spina Bifida and Hydrocephalus. The study "Factors affecting survival of infants with myelomeningocele in southeastern Uganda" is published in the *Journal of Neurosurgery: Pediatrics*, Feb 2011 / Vol. 7 / No. 2 / Pages 127-133.

<http://thejns.org/doi/abs/10.3171/2010.11.PEDS10428>

## Small business with big results

In 2009 Jackie was born with Spina Bifida in Uganda. Her mother Jackline was sent to Mbarara University Hospital where she was referred to OURS. At OURS Jackline learned about her daughter's condition and also discovered that Jackie was not the only child with Spina Bifida. Jackie was operated on at the CURE Hospital in Mbale and receives follow-up care at OURS, Mbarara. Jackline joined the parent support group where she learned about income generating activities. With the financial help from a friend she was able to start her own needlecraft business, making embroidered tablecloths. She is now able to look after her family, take Jackie to OURS for follow-up care and attend all the parent meetings. She now encourages other parents to find ways to support themselves and their children, and spreads awareness about Spina Bifida and Hydrocephalus at every opportunity.



Before treatment, at home.

## Lucy's baby received treatment at CURE

In January, IF president Pierre Mertens visited CURE Children's Hospital in Mbale, Uganda, for their 10th anniversary celebrations. While in Uganda, Pierre learned of a young mother and child whose story ran in *The Daily Monitor* newspaper at the time. He met Lucy, a 17-year-old mother with a baby suffering from Hydrocephalus who was born on March 15, 2010. In spite of Lucy's desperate search for help, her baby boy received no treatment. Thanks to individual donations and the intervention of Rebecca from IF Child Help Uganda, they came to CURE and the baby was operated on. A follow-up article about CURE and its work to treat Hydrocephalus was published after the celebrations.

In the hospital to be taken care of.



## Uganda's Miracle Babies

Channel 4's Jenny Kleeman travelled to Mbale, Uganda, to report on the situation of children with Spina Bifida and Hydrocephalus in Uganda for the Channel 4 show "Unreported World". She found that prejudice and lack of knowledge prevents mothers to provide the best care for their children when confronted with Hydrocephalus. IF facilitated this documentary by connecting Mrs Kleeman to our partners in Uganda. The documentary was also aired in Belgium and is therefore an important milestone in raising awareness on Hydrocephalus in developing countries. Channel 4 is one of UK's main and most viewed TV channels.

The 22 minute documentary can be viewed here:  
<http://www.channel4.com/programmes/unreported-world/4od#3268221>



## Francesca Maina's Miracle Baby Jeremy

*"During my teenage life I had little hope of ever dating or even getting married. I had already undergone a lot of social challenges that made me feel inadequate. But I met a caring and loving man. We had to overcome some obstacles before we could have our wedding. But with love and support from my husband, we were able to overcome all of them.*



*One year before our wedding, I started taking a daily dose of 4.0mg folic acid. My gynecologist assured us it was possible to get our own baby. We had to wait for four more years, but then one Sunday morning: the laboratory test confirmed my pregnancy!!*

*During a visit of the local maternal healthcare clinic, it was discouraging to find that the nurses were no help at all. They even did not advise me about the importance of taking folic acid. They rarely supply folic acid tablets to (future) mothers although they had them in store. Before leaving I tried to create some awareness why folic acid is a must.*

*As my body weight gradually increased, my doctor advised me to take good care of my feet to avoid complications such as pressure sores. At six months, I started using a wheelchair during the working hours to avoid straining my lower extremities.*

*On 26 May 2011, during the 39th week of pregnancy, I was taken into the operating room for a caesarean section. As I breastfeed Jeremy or change diapers, my heart is overwhelmed with the joy of being a mother. My promise to all young women born with Spina bifida and with a desire for babies: don't be afraid - IT IS ALL POSSIBLE!"*

# Numbers and achievements in 2011

## Surgeries

- **1.985** shunts delivered to **24** partners in **17** countries.
- **1.946** shunt operations performed by the projects
- **571** ETV operations by CURE Hospital in Mbale, Beit CURE in Lusaka, Zambia, Queen Elisabeth Hospital in Blantyre, Malawi and Bethany Kids in Kijabe, Kenya
- **693** SB operations performed by the projects

## Children in follow up

- **16.712** children being followed in their rehabilitation and development
- **3.737** children are actively participating in a continence management program

## Training

- Annual workshop on Spina Bifida and Hydrocephalus Interdisciplinary Program (S.H.I.P.) held in Kampala, Uganda in November 2010: **68** participants from **11** countries
- **93** trainings in continence management were organized for parents and their children
- **36** trainings for parents were organized, other than on continence management
- **13** trainings for youth with Spina Bifida and/or Hydrocephalus were organized

## Inclusion

- **105** children gone to school as a result of proper continence management
- Youth representatives are becoming more active in the support groups. Currently **30** youth are actively representing their peers in the support group committees.
- More schools are being targeted in sensitization activities and are taking active part in the activities of our local partners. In total **165** schools are part of our local network.

## Parent group building

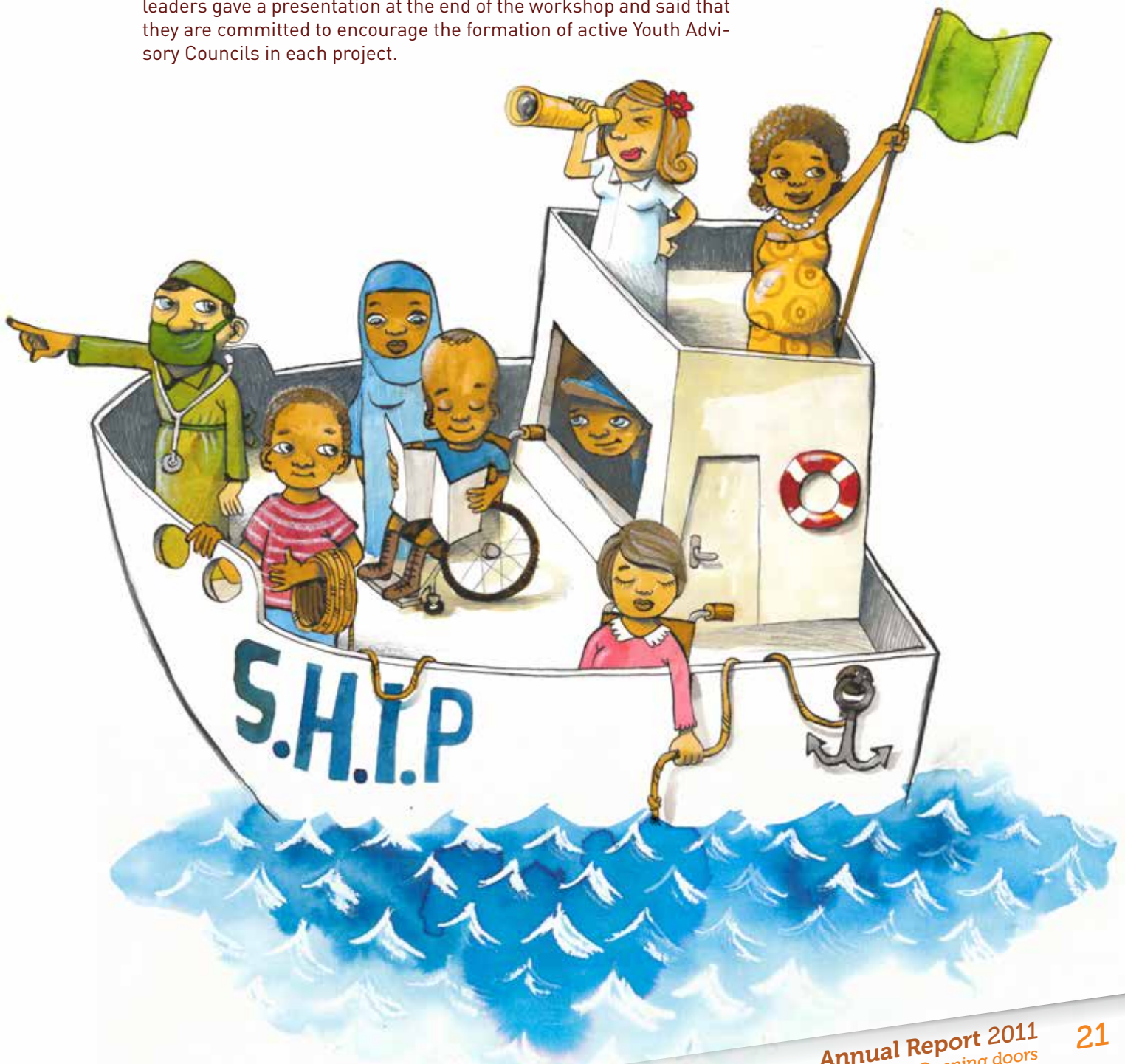
- **109** parent meetings were organized by the projects, attended by more than **3.400** parents

## Prevention

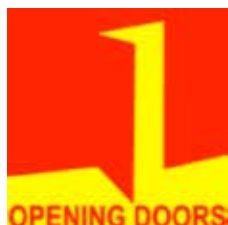
- Around **384.000** Folic Acid tablets were distributed to approximately **3.350** women

## IF African Workshop 2011 Sailing Off

68 parents, patients, healthcare professionals and coordinators from 11 different countries gathered in Uganda from 1-4 November for the workshop "Sailing off" organized by IF. The theme of this workshop was interdisciplinary care. The idea to create a SHIP -Spina Bifida and Hydrocephalus Interdisciplinary Program- was presented and welcomed by all participants. The importance of networking and collaboration were discussed in most working sessions and presentations. Youth and adults with Spina Bifida and Hydrocephalus made the first steps in creating an International Youth Network. The young leaders gave a presentation at the end of the workshop and said that they are committed to encourage the formation of active Youth Advisory Councils in each project.



## IF Annual Conference "Opening Doors"



The Asociación Guatemalteca de Espina Bifida (AGEB) and the International Federation for Spina Bifida and Hydrocephalus (IF) co-organised IF's 22nd International Conference on June 10-12, 2011 at the Convention Center of the Westin Camino Real Hotel in Guatemala City. About 200 participants including children and adults with Spina Bifida, their families, physicians, nurses, doctors, policy makers as well as students in the fields of nutrition, public health, psychology and physiotherapy gathered to share and discuss information and matters related to Spina Bifida and Hydrocephalus.

The conference was opened by Guatemala's vice president Dr. José Rafael Espada.

## IF General Meeting

During the General Meeting 2011 in Guatemala City, IF members said farewell to board member and treasurer Teije Dijk, who served on the IF board since 2000. IF is very grateful for his strong commitment and valuable contributions. The General Meeting elected Elena Monzón de Zappoli, president of IF's member association in Argentina, APEBI, and SHINE's chief executive Jackie Bland from the UK, as board member and co-opted board member respectively. Three applications for IF membership were approved during the meeting: the Northcott Spina Bifida group (Australia), Fundacja Spina (Poland) and Hellenic Association for Spina Bifida and Hydrocephalus (Greece).

## EU Workshop Capacity Building in Budapest

On the 29th of May IF organised a workshop in Budapest on capacity building for people with Spina Bifida and Hydrocephalus, in collaboration with MEOSZ, the National Federation of Disabled Persons' Associations in Hungary. IF President Pierre Mertens led the workshop and motivated the participants to create an organisation of people with Spina Bifida and Hydrocephalus in Hungary. He explained why it is important to have a Spina Bifida

and Hydrocephalus association in Hungary. United in an association, people with these conditions, and their parents, can better defend their rights. Through the international collaboration with IF, associations can gather and exchange knowledge that will help to improve the lives of people with Spina Bifida and Hydrocephalus. Their needs are very complex and they have the right to correct multidisciplinary treatment and care and to live their lives equal to others.

## EU Workshop: Adults and now?

36 parents, patients and healthcare professionals from 16 different European countries were gathered in Leuven on 24 September 2011 in the frame of the workshop, "Adults, and

now? Access to services and healthcare for youth and adults with Spina Bifida and Hydrocephalus" organized by IF to discuss the challenges of youths and adults with Spina Bifida and Hydrocephalus. The Gasthuisberg clinic in Leuven and the Adult Multi-disciplinary clinic at Chelsea & Westminster Hospital in London were presented as the best and exceptional examples of multidisciplinary care service for adults with Spina Bifida and Hydrocephalus in Europe. Dr. Paige Terrien Church from the University of Toronto and Dr. Helen Healy and Dr. Joanne Maxwell from the Rehabilitation Institute and Holland Bloorview Kids Rehab in Canada exposed the issues of transition from a holistic perspective and shared their service model of transition.

**Adults,  
and now?**

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

## Launch of IF's new website

The International Federation for Spina Bifida and Hydrocephalus launched a new website in December 2011. With an improved structure and renewed design, the website combines workability and comfort. Information is easy to find and accessibility standards have been respected.

## Conference Spina Bifida and Hydrocephalus anno 2011 in recognition of Carla Verpoorten

Over 300 people, including patients, health professionals, friends and family members, gathered on the 24th of September 2011 in Leuven to salute Dr. Carla Verpoorten, retiring renowned Spina Bifida expert from the University Hospital in Leuven, Belgium. The ceremony was presented in a conference entitled "Spina Bifida and Hydrocephalus anno 2011" organised by the University of Leuven in collaboration with IF. Dr. Verpoorten remains IF's medical consultant on multidisciplinary care as well as treatment of Spina Bifida and Hydrocephalus in developing countries.



Dr. Carla Verpoorten

## IF Award 2011 – World Pediatric Project

At IF's 22nd International Conference in Guatemala the IF Award 2011 was presented to the World Pediatric Project. The organisation was founded in 2001 as the International Hospital for Children, with the mission to connect worldwide pediatric surgical, diagnostic and preventative resources to heal critically ill children in developing countries in the Caribbean and Central America. On March 1, 2011, the International Hospital for Children merged with Healing The Children Missouri and became the World Pediatric Project (WPP).

Dr. Kinloch Nelson accepted the IF Award 2011 on behalf of the World Pediatric Project and was very thankful and honoured for the recognition of the organisation's work. WPP also develops prevention programmes and looks forward to cooperate with IF in the prevention of neural tube defects.

## Portraying Persons with Spina Bifida and Hydrocephalus

IF has started a long term collaboration with the Royal Academy for Fine Arts (Koninklijke Academie voor Schone Kunsten – KASK) to have photography students develop positive images of persons with Spina Bifida and Hydrocephalus. All too often, the image of life with these disabilities is very negative, too negative.

The first phase of the project, having two students taking photographs in very different environments for three months, had a very rewarding outcome. Both photography students returned with a wide variety of positive and powerful images.



IF board member, Dr Erwin Calgua | Dr. Kinloch Nelson and IF president, Pierre Mertens

# Members of the International Federation for Spina Bifida and Hydrocephalus

## Algeria

Association des malades de Spina Bifida de Mostagenem  
villa no83 chemins de crêtes  
(Mazagran)  
Mostagenem 27120  
[www.spinabifida27.unblog.fr](http://www.spinabifida27.unblog.fr)

## Argentina

Asociación Para la Espina Bífida e Hidrocefalia (APEBI)  
Fragata Presidente Sarmiento 831  
C1405AXB Ciudad Autónoma de Buenos Aires  
[www.apebi.org.ar](http://www.apebi.org.ar)

## Australia

Spina Bifida Association  
Queensland  
21 Tillot Street  
Dutton Park  
Queensland  
<http://spinabifida.org/>

The Northcott Spina Bifida Group  
- a program of Northcott Disability Services  
The Northcott Building  
PO Box 4055  
Parramatta NSW 2124  
New South Wales  
[http://www.northcott.com.au/spina\\_bifida\\_group.php](http://www.northcott.com.au/spina_bifida_group.php)

## Austria

Spina Bifida und Hydrocephalus Österreich (SB&HÖ)  
Goldlackgasse 10  
1220 Vienna  
[www.sbho.at](http://www.sbho.at)

## Belgium

Vlaamse Vereniging voor Spina Bifida en Hydrocephalus vzw (VSH)  
Spiegel 13  
9860 Oosterzele-Scheldewindeke  
[www.spinabifida.be](http://www.spinabifida.be)

## Brazil

Associação de Espinha Bífida e Hidrocefalia do Rio de Janeiro (AEBH)  
Av. Prefeito Dulcídio Cardoso, 2.500  
Bloco 1 Apt. 606 - Barra da Tijuca  
22631- 051 Rio de Janeiro  
[www.aebh.org](http://www.aebh.org)

## Canada

Spina Bifida and Hydrocephalus Association of Canada (SBHAC) / Association de spina-bifida et d'hydrocéphalie du Canada (ASBHC)  
428-167 av. Lombard Avenue  
Winnipeg, MB R3B 0V3  
[www.sbhac.ca](http://www.sbhac.ca)

## Colombia

Fundación Sin Barreras  
Calle 74 N°38 C-07  
Barranquilla, Atlántico  
Republic of Colombia  
[www.fundacionsin-barreras.org/index.htm](http://www.fundacionsin-barreras.org/index.htm)

## Croatia

Udruga osoba i roditelja djece sa spinom bifidom "Aurora"  
Prilaz Monte Cappellet 1  
52100 Pula  
<http://www.spinabifida.hr>

## Denmark

Rygmarvsbrokforeningen af 1988  
Hoptrup Kirkeby 11  
6100 Haderslev  
[www.rygmarvsbrokforeningen.dk](http://www.rygmarvsbrokforeningen.dk)

## Estonia

The Estonian MMC and HC Society  
Tervise 28  
13419 Tallinn

## Finland

Suomen CP-liitto ry  
Malmin Kauppatie 26  
00700 Helsinki  
[www.cp-liitto.fi](http://www.cp-liitto.fi)

## France

Fédération Française des Associations du Spina Bifida (FFASB)  
58 rue Pré Commun  
31230 L'isle en Dodon  
[www.spinabifida.fr](http://www.spinabifida.fr)

## Germany

Arbeitsgemeinschaft Spina Bifida und Hydrocephalus (ASBH)  
Münsterstrasse 13  
44145 Dortmund  
[www.asbh.de](http://www.asbh.de)

## Greece

Hellenic Association for Spina Bifida and Hydrocephalus  
3 Levidou Street  
14671 Nea Erythrea - Athens  
[www.appac.gr](http://www.appac.gr)

## Guatemala

Asociación Guatemalteca de Espina Bífida (AGEB)  
9a avenida 46-63 zona 12,  
Monte María 3, Ciudad de Guatemala  
[ebguatemala.blogia.com/](http://ebguatemala.blogia.com/)

## Honduras

Fundación Amado Josue  
Colonia Castaños Sur  
Frente a CNBS, Casa #3002  
Tegucigalpa  
<http://fundacionamadojosue.org/>

## Ireland

Spina Bifida Hydrocephalus Ireland (SBHI)  
Old Nangor Road  
Clondalkin, Dublin 22  
[www.sbhi.ie](http://www.sbhi.ie)

## Italy

Associazione Spina Bifida Italia (ASBI)  
Via Duomo 20  
29020 Settima di Gossolengo (PC)  
[www.asbi.info](http://www.asbi.info)







**Japan**

Spina Bifida Association of Japan  
Otaku Nakarokugo 4-13-10-214  
Tokyo

**Luxembourg**

Association pour le Spina Bifida  
a.s.b.l.  
5 Chemin de Bousberg  
Boîte Postale 20  
L-7703 Bissen  
[www.spina-bifida.lu/](http://www.spina-bifida.lu/)

**Mexico**

Asociación Mexicana de Espina  
Bifida, A.C. (AMEB)  
Calle Maurice Baring # 295  
Col. Jardines de la Patria  
C.P. 45050  
Zapopan, Jalisco

**The Netherlands**

BOSK Work Group Spina Bifida &  
Hydrocephalus  
Postbus 3359  
NL-3502 GJ Utrecht  
[www.bosk.nl](http://www.bosk.nl)

**Norway**

Ryggmargsbrokk- og  
hydrocephalusforeningen  
Brynsveien 96  
N-1352 Kolsås  
Norway  
[www.ryggmargsbrokk.org](http://www.ryggmargsbrokk.org)

**Peru**

Asociacion Peruana de Espina  
Bifida e Hidrocephalia Arequipa  
(APEBHI)  
Av Jorge Chavez 527  
Cerado Arequipa

Asociación de Espina Bífida e  
Hidrocefalia del Perú (ASESBIH  
PERÚ)  
Av. La Capilla 1151, Dpto. 301  
Rímac, Lima 25  
[www.asesbihperu.org](http://www.asesbihperu.org)

**Poland**

Stowarzyszenie Chorych z  
Przepuklin Oponowo-Rdzezeniow  
R.P. (ASBP)  
ul. elazowej Woli 20/39A  
20-853 Lublin  
[spinabifida.w.interia.pl](http://spinabifida.w.interia.pl)

Fundacja "Spina"  
Tysiaclecia 39/15  
40-875 Katowice  
[www.spina.com.pl](http://www.spina.com.pl)

**Portugal**

Associação Spina Bifida e  
Hidrocefalia de Portugal (ASBIHP)  
Rua Botelho Vasconcelos  
Lote 567 C/D  
1900-637 Lisbon  
[www.asbihp.pt](http://www.asbihp.pt)

**Romania**

Asociatia Romana de Spina Bifida si  
Hidrocefalie  
Strada Secuilor Nr 7, Bloc B31, Sc.3  
Et.2, Ap.38  
Sector 4, Bucuresti  
[www.arsbh.ro/](http://www.arsbh.ro/)

**Russia**

Association of Spina Bifida and  
Hydrocephalus St. Petersburg  
SPb. Stachek prosp. 356  
198097 St. Petersburg

**Scotland**

Scottish Spina Bifida Association  
(SSBA)  
The Dan Young Building  
6 Craighalbert Way  
Dullatur  
Cumbernauld G68 0LS  
[www.ssba.org.uk](http://www.ssba.org.uk)

**Serbia**

Spina Bifida and Hydrocephalus  
Association of Serbia  
Milesevska 40  
11000 Beograd  
Republic of Serbia

**Slovakia**

Slovenská spoločnosť pre spina  
bifida a/alebo hydrocefalus, o.z.  
SNP 14  
919 04 Smolenice  
[www.sbah.sk](http://www.sbah.sk)

**Spain**

Federación Española de  
Asociaciones de Espina Bífida e  
Hidrocefalia (FEBHI)  
Pechuán 14, local 6  
28002 Madrid  
[www.febhi.org](http://www.febhi.org)

Associació Catalana d'Espina Bífida  
i Hidrocefàlia  
Sorolla 10, Baixos  
Barcelona 08035  
[www.espinabifida.cat](http://www.espinabifida.cat)

**Sudan**

Spina Bifida Federal Association  
Cheshire Home Building  
El Taif Area  
Khartoum

**Sweden**

Riksförbundet för Rörelsehindrade  
Barn och Ungdomar (RBU)  
Box 8026  
104 20 Stockholm  
[www.rbu.se](http://www.rbu.se)

**Switzerland**

Schweizerische Vereinigung Spina  
Bifida und Hydrocephalus (SBH)  
Rue du Joliment 22  
2525 Le Landeron  
[www.spinahydro.ch](http://www.spinahydro.ch)

**Turkey**

Spina Bifida Derneği  
858 Sokak No: 9 Kat: 4/405  
Paykoc ishani  
35250 Konak / Izmir  
[www.spinabifida.org.tr](http://www.spinabifida.org.tr)

**UK**

Shine – Spina Bifida Hydrocephalus  
Information Networking Equality  
42 Park Road  
GB-Peterborough PE1 2UQ  
<http://www.shinecharity.org.uk/>

**USA**

Spina Bifida Association of America  
(SBAA)  
4590 MacArthur Boulevard NW  
Suite 250  
Washington DC 20007-4226  
[www.sbaa.org](http://www.sbaa.org)

# Financial Results

## Statement of the auditor

Report of the auditor on the financial statements for the year ended 31-12-2011 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 31-12-2011, prepared under the responsibility of the board of directors of the federation, which show a balance sheet total of € 325.760,63 and a loss for the year of € 11.934,93.

## Unqualified audit opinion on the financial statements

Our audit was planned and performed to obtain reasonable assurance about whether the financial statements are free of material misstatement. Federation officials have responded clearly to our requests for explanations and information. On a test basis, we have examined the justification for the amounts included in the annual accounts. We have assessed the accounting policies, the significant accounting estimates made by the federation and the overall financial statement presentation. We believe that our audit provides a reasonable basis for our opinion. In our opinion, taking into account the legal and regulatory requirements applicable in Belgium, the financial statements for the year ended 31/12/2011 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 modify our audit opinion on the financial statements :

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

Lennik, March 19th 2012

BVBA De Nul & co  
bedrijfsrevisor  
Auditor

represented by  
Roger De Nul



## Balance sheet at 31 December 2011

<b>Assets</b>	<b>31-Dec-11</b>	<b>31-Dec-10</b>
<b>Tangible assets</b>	<b>3.876,33</b>	<b>6.089,82</b>
Investments	11.965,74	11.965,74
Depreciations investments	-10.766,89	-9.268,97
Office furniture	3.577,83	3.577,83
Depreciations office furniture	-1.431,14	-715,57
Cautions	530,79	530,79
<b>Amounts receivable</b>	<b>82.728,06</b>	<b>116.477,72</b>
Customers	22.254,96	36.067,41
Subsidies to receive	47.763,65	25.000,00
Divers to receive	737,78	1.132,00
If child help current account	11.971,67	54.278,31
<b>Bank &amp; cash accounts</b>	<b>233.750,04</b>	<b>278.421,25</b>
<b>Transit accounts</b>	<b>5.406,20</b>	<b>7.388,39</b>
Costs for next year	5.406,20	7.352,23
Profits for this year	36,16	0,00
<b>Total assets</b>	<b>325.760,63</b>	<b>408.377,18</b>

<b>Liabilities</b>	<b>31-Dec-11</b>	<b>31-Dec-10</b>
<b>Reserves</b>	<b>248.347,70</b>	<b>260.282,63</b>
Funds of if	260.282,63	254.476,79
Profit-loss bookyear	-11.934,93	5.805,84
<b>Amounts payable</b>	<b>77.412,93</b>	<b>75.300,61</b>
Suppliers	16.491,83	34.387,57
Taxes to be paid	2.380,18	574,00
Salaries to be paid	2.765,00	1.295,84
Provision holiday fee	21.155,19	14.361,42
Projects current accounts	33.459,68	24.681,78
Divers to pay	1.161,05	0,00
<b>Transit accounts</b>	<b>0,00</b>	<b>72.793,94</b>
Profits for next year	0,00	72.793,94
<b>Total liabilities</b>	<b>325.760,63</b>	<b>408.377,18</b>

## Profit and loss 2010

### OUT in euro

<b>Diverse costs</b>	<b>503.819,47</b>
Housing costs	20.246,50
Office supplies	5.823,57
Publications - copy	3.823,52
Communication costs	7.603,44
Membership fees	900,00
Shipping costs	945,85
Bookkeeping	4.173,89
Social & medical secretariat	4.052,31
Translations	1.142,20
Audit	1.542,75
Consulting (Flour fortification)	49.801,08
Consulting (External Evaluation)	1.998,00
Other fees (IT, Lay-out)	2.702,45
Insurance	1.944,58
Travel costs	69.316,39
Official documents (visas)	603,93
Hotel and subsistence	36.013,28
Projects: Medical material	71.469,79
Projects: Salaries	86.603,35
Projects: Training	24.576,67
Projects: Treatment & rehabilitation	4.943,11
Projects: Research	3.227,19
Projects: Parent meetings	24.498,89
Projects: Prevention	5.338,81
Projects: Sensitization & Advocacy	2.548,67
Projects: Administration	8.214,28
Projects: Other costs	411,60
Conferences - meetings	59.353,41
<b>Salary costs</b>	<b>217.561,63</b>
<b>Depreciations</b>	<b>9.256,56</b>
<b>Financial costs</b>	<b>3.449,21</b>
<b>Exceptional costs</b>	<b>5.495,06</b>
<b>Total costs</b>	<b>739.581,93</b>

## IN in euro

<b>General income</b>	<b>690.394,72</b>
Membership fees	8.010,00
Bayer*	60.000,00
Akzo Nobel°	25.000,00
Other grants	16.062,41
Subsidies Norad (through RHF)	261.530,83
Subsidies project SHIA (through RBU)	59.814,38
Support Child Help Belgium	53.762,47
EU Progress Programme	132.500,00
Millennium Agreements	73.714,63
<b>Diverse recuperation</b>	<b>33.650,48</b>
Financial income	2.841,30
Exceptional income	760,50
<b>Total income</b>	<b>727.647,00</b>
<b>Result</b>	<b>-11.934,93</b>

\*IF thanks Bayer Healthcare for their in-kind contribution for the NTD prevention campaign in Europe, for details check [http://www.bayerpharma.com/en/corporate\\_responsibility/access\\_to\\_medicines/joint\\_efforts/patient\\_organizations](http://www.bayerpharma.com/en/corporate_responsibility/access_to_medicines/joint_efforts/patient_organizations)

°Akzo Nobel NV supports IF to reach the necessary matching funds for the subsidies of the Dutch government (Millennium Agreements)



# IF Partners

## Partners

The International Federation for Spina Bifida and Hydrocephalus has expanded its international network tremendously. IF was represented or active in the following organisations, or IF was supported by the following organisations during the course of the year.

## International Institutions



## International Partnerships



## Other International NGOs



## Companies





**Text:**

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**Pictures:**

Lieven Bauwens, Io Cooman, Sharan Lontho, Renée Jopp, Pierre Mertens

**Lay out and Illustrations:**

Bert Dombrecht

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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  
Directorate-General Employment, Social Affairs and Equal Opportunities  
Integration of People with Disabilities - Unit G3





**IF ivzw**

International Federation for Spina Bifida and Hydrocephalus  
Consultative status special category, Economic and Social Council of the United Nations,  
Participatory Status, Council of Europe

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**INTERNATIONAL  
FEDERATION  
for  
SPINA BIFIDA  
and  
HYDROCEPHALUS**