



Annual report 2010



Annual Report 2010

What's the next step

Presented on the General Meeting of the International Federation for Spina Bifida and Hydrocephalus

10-12 June 2011

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Introduction

Introduction

What's the next step?

IF, the International Federation for Spina Bifida and Hydrocephalus, is a special worldwide network of knowledge, which includes adults and children with Spina Bifida and Hydrocephalus, their relatives, devoted professionals, researchers and volunteers. This alliance of committed persons is special because it enables the IF knowledge network to cover all aspects of life. Knowledge, after all, is the key to a better life. The IF knowledge networks strives for the right to a decent life and accurate care for children and adults with Spina Bifida and Hydrocephalus, all over the world.



In 2010, IF organised or contributed to conferences and workshops in Dar Es Salaam (Tanzania) on neurosurgery and parent groups, in Brussels (Belgium) on preconception care and preconception health, in Cape Town (South Africa) with the Flour Fortification Initiative, in Hue (Vietnam) together with Handicap International, in Milan on prenatal surgery and in Varese on ethics (Italy), in Bucharest (Romania) with the World Health Organisation, in Karthoum (Sudan), in Nairobi (Kenya) on the harmonization of fortification standards and in Kigali (Rwanda).

Our 21st international conference was very well attended, and splendidly organised by our Irish member association, Spina Bifida Hydrocephalus Ireland, under the theme **"What's the next step?"**.

What is the next step? What is our destination and how can we reach it? Persons living with Spina Bifida and Hydrocephalus know that achievable goals prevent frustration and discouragement. The pleasant thing about walking is that you move forward step by step. In our rushed society we tend to run without thinking.

"What's the next step?" starts with questioning previous steps and the destination. At every step we can decide to stop, to go further or to go somewhere else. A successful step will invite us to continue our journey; after each failure we can pause for a while and see if we have to adjust our goal.

In this annual report you can look back with me to a successful year in which IF planned the future for our Spina Bifida and Hydrocephalus community worldwide.

From our mission "improve the quality of life for persons with Spina Bifida and Hydrocephalus and primary prevention", the IF board defined 4 working domains:

- IF as a **human rights** advocate, voicing the concerns of our target group
- Primary **prevention**, advocating food fortification, awareness campaigns and stimulating research
- **International solidarity** in favour of our target group in developing countries
- **Network development** focusing on widening and empowering our own network and networking at global level.

Let's take steps in the care for Spina Bifida and Hydrocephalus, in our associations, in IF's four domains. There is work to do. In Dublin the message was clear: we have no time to lose. Adults with Spina Bifida and Hydrocephalus need and deserve lifelong coordinated care. The next step is making a start towards this important goal.

Although 2010 was a year of global crisis, IF managed very well and can proudly report a financial growth of nearly 40%. However, numbers don't tell the whole story; they only show a continued interest in IF's activities and an increased financial participation of member organisations at international level. The actual work is done by you, by our member associations, many volunteers, by the IF staff, and donors.

My next step will be towards you.

IF, even as a fast growing organisation, is and should always be a network of people. I will approach you to be involved in our network of knowledge, and with you and your support we can improve the life for all concerned with Spina Bifida and Hydrocephalus.

Join our walk to a better life in a better world.

Pierre Mertens
President IF

2010 Through the Eyes of Protagonists

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.

Major achievements in 2010:

IF as an organisation

Expansion IF staff with a European Projects Coordinator
Expansion of the IF office

Prevention

Close cooperation with FFI
NTD report "Act against Europe's most common birth defects"
IF EU Workshop Lobbying
Smarter Futures
1st European Congress Preconception Care and Preconception Health
1st NeuroNet meeting

Human Rights

Partnering with the European institutions (EU, EC, EP, EDF) as NGO representing people with Spina Bifida and Hydrocephalus
Publication Equality in Healthcare (Eastern Europe)
Draft Position Paper Prenatal Counselling

Development Cooperation

Over 3,000 surgeries, over 6,000 children in follow-up
1 neurosurgeon trained in the IPATH programme
IF African Workshop 2010, "Strengthening parent groups"
2nd African FFI Meeting, Cape Town, South Africa
Meeting with MPs Uganda

Knowledge Network

Successful annual conference in Ireland
Three new members
IF EU Workshop Capacity Building
Development of volunteer network

Financial Stability

Achieving EU funding for 2010 onwards
Continuing private donor support
Ongoing financial commitment from Norway and Sweden

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
Mr. Douglas Sorocco - USA
Mr. Jon Burke - UK
Dr. Erwin Calgua - Guatemala
Mrs. Renée Höglin - Sweden
Mrs. Eva Toft - Sweden
Mr. Luís Quaresma - Portugal
Mrs. Thelma Cloake - Ireland
Mrs. Maria Cristina Dieci - Italy
Dr. Margo Whiteford - Scotland (UK)

The board met in person in June and November 2010.

Staff

Brussels office

Mr. Lieven Bauwens - Secretary General
Mrs. Katalijne Van Diest - Coordinator Development Cooperation
Mrs. Renée Jopp - Communications officer
Mr. Tom Rottinghuis - Coordinator European Projects

Mr. Lieven Bauwens
Mrs. Eli Skattebu
Mr. Pierre Mertens
Mr. Teije Dijk
Mr. Luís Quaresma
Mrs. Renée Höglin
Mrs. Thelma Cloak
Mr. Douglas Sorocco
Not pictured:
Mr. Jon Burke
Mrs. Maria Cristina Dieci





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.

IF is a founding member of IF Child Help Belgium (11 September 2006), an organisation that focuses on Development Cooperation. IF is part of the Leaders Group of the Flour Fortification Initiative (FFI), and a member of the Belgium Disability and Development Cooperation Initiative "1 op 10" ("one in ten").

The IF president holds board member status at the European Disability Forum (EDF), the Bo Hjelt Foundation, the Flemish Spina Bifida and Hydrocephalus Association and is a member of the General Assembly of Light For The World Belgium.

Board members of IF liaise in their national organisation's name with Atlas Alliance/NORAD (Norway) and SHIA (Sweden) to serve children with Spina Bifida and Hydrocephalus in Africa.

IF Consultative team

Mrs. Vero Van Den Abeele - consultant IF Knowledge Network
Prof. Dr. Lieven Annemans - Health Economics
Mrs. Sofie Blancquaert - legal and ethics consultant IF, lawyer Chemiphar
Dr. Richard Bransford - general surgeon, MD, FACS
Mrs. Theresa Cole, Mr. Eric Holdtgrefe, Mrs. Annie Van Thienen - translator
Dr. Jan Cordonnier and Mrs. Annick Uytterhaegen - laboratory
Mrs. Myleen Christiaens - consultant continence management
Dr. Filippo Ciantia - tropical medicine
Mr. Zjuul Devens - multimedia, photography and camera work
Dr. Philippe Gillis - consultant paediatrics and tropical medicine
Frank De Graeve - communications advice
Dr. Guy De Groot - Folic Acid working group Belgium
Mrs. Helen Healy - consultant life skills and transition
Mr. Bo Hjelt - consultant fundraising and general management
Ms. Sofie Van Houtte, Mrs. Annie Van Thienen - user representation
Prof. Dr. Emmanuel Keirse - user counselling
Mr. Ludo Longin - DCS
Prof. Dr. Glen Maberly - Flour Fortification Initiative
Mrs. Marjan Van Mourik - consultant management and fundraising IF
Dr. Joe Mulinare - prevention expert, Centers for Disease Control and Prevention
Dr. Martina Oneko - medical consultant IF, consultant paediatrics/neuro-paediatrics
Mr. Joris Petillion - commercial advice
Prof. Dan Poenaru - medical consultant, paediatric neurosurgeon
Mr. Andrew Russell - senior advisor flour fortification
Mr. Koen Sevenants - senior advisor Development Cooperation Asia
Prof. Dr. Regine Steegers-Theunissen - professor in reproductive epidemiology
Mr. Dirk Van Den Steen - consultant Health Economics
Mr. Paul Van Steenvoort - development cooperation
Dr. Carla Verpoorten - medical consultant, neuro-paediatrician
Dr. Anna Verster - senior consultant Flour Fortification Initiative
Prof. Dr. Patrick De Vlieger - anthropology and disability
Dr. Benjamin C. Warf - medical consultant, paediatric neurosurgeon, ABNS, ABPNS
Prof Eric Borgstein - surgeon Beit Cure Hospital Malawi
Kordelia Fischer-Borchert - OURS Program Director (2010)

conference with his speech "Why should we prevent who we love?". He emphasized that prevention should never involve a value judgment on those living with Spina Bifida.

During the conference IF also underlined the importance of the involvement of organisations of people with disabilities and presented its draft position paper on prenatal counselling.

IF Board Member Dr. Margo Whiteford, president of the Scottish Spina Bifida Association, consultant geneticist and senior lecturer in Medical Genetics at the University of Glasgow, led a remarkable workshop on genetic counselling, and US public interest lawyer and IF volunteer James E. Wilkinson presented an important lecture on ethics, disability stereotypes and international human rights. On the closing day of the conference a list of recommendations was drawn up as a proposition to the Ministers of Health of European Governments.



Dr. Margo Whiteford - IF board member, Scotland

Smarter Futures

Harmonisation Workshop

Through its partnership in the Smarter Futures project, IF facilitated a Harmonisation Workshop in Nairobi, Kenya, in April 2010. Representatives of 15 African countries at different stages of developing flour fortification programs, met in Nairobi, Kenya, 19-22 April 2010 to consider the evidence-based science behind various flour fortification guidelines, including the 2009 WHO consensus statement designed to assist countries in developing standards.

Substantial vitamin and mineral deficiencies exist in sub-Saharan Africa, and food fortification, as a sustainable long-term approach with other nutrition interventions, has the potential to address this significant problem.

The Nairobi workshop built on progress made during the 2008 FFI workshop in Arusha, Tanzania. Both workshops were attended by participants from government standard setting and enforcement organisations; other government leaders; flour millers; bakers; regional economic communities and institutions; civil society; academia; vitamin and mineral pre-mix suppliers; as well as international development partners.

2nd African FFI Meeting

On 26 November 2010 IF participated in the 2nd African FFI Meeting in Cape Town South-Africa. The FFI / Smarter Futures meeting celebrated the successes countries are making toward fortification as a strategy to reduce vitamin and mineral deficiencies. The meeting took place following the 21st Annual Meeting of the International Association of Operative Millers (IAOM) Mideast and Africa District Conference and Expo. A total of 73 participants from 21 different countries benchmarked progress in their respective countries and discussed strategies to overcome barriers.

During the 2nd African FFI Meeting, Mr. Salih Abdel Wahab Mohamed, Quality Control Manager and a mill engineer for Wheata Industrial Company Ltd. in Sudan, received the FFI Leadership Award for leading his company's efforts to fortify flour with iron and folic acid. Mr. Salih's work with flour fortification in Sudan began in 2001 when the company started its operations. The company adopted voluntary fortification of all of its wheat flour in 2005 as a matter of corporate social responsibility. It is the only milling company in Sudan to voluntarily fortify flour.

In 2010 both Senegal and Mauritania issued a mandate that wheat flour milled in their countries should be fortified with at least iron and folic acid. Worldwide, 60 countries now have legislation or decrees that mandate fortification of one or more types of flour with either iron or folic acid.

NeuroNet

In collaboration with the Bo Hjelt Foundation IF organised the 1st NeuroNet meeting. On October 6, 2010, a scientific meeting took place between top-level researchers on the prevention of Spina Bifida. This newly founded group of experts, called NeuroNet, is aiming to start a consortium which will pool all knowledge on the development of neural tube defects. The initiative was started by the Bo Hjelt Foundation through its board members Professor Régine Steegers-Theunissen and Professor Andrew Copp, and facilitated by IF. The meeting offered researchers from various European countries an opportunity to learn from each other's studies and methods and to find ways to combine their efforts. It is clear that many genes are involved in the development of neural tube defects and a lot more research is needed to find the true cause of Spina Bifida. This knowledge is key in the search for even more effective prevention measures, since not all cases seem to be folate related. IF was represented at the meeting by its President Pierre Mertens, board member Margo Whiteford, and Secretary General Lieven Bauwens. IF's president gave a moving speech about prevention of neural tube defects from a parent's perspective.

WHO resolution birth defects

IF responded to the draft WHO Resolution Birth Defects, EB126.R6, as prepared by WHO's Executive Board for its meeting on 21 January 2010. IF welcomed the WHO Resolution and shared WHO's view that birth defects should be recognised as priorities in public health. IF supported the WHO's call to Member States to raise awareness about the importance of birth defects as a cause of child morbidity and mortality, and to integrate effective interventions into existing maternal, reproductive

and child health services and social welfare for all individuals who need them. IF has always been a strong advocate for primary prevention and multidisciplinary care. IF also recognises the need to strengthen research and studies on etiology, diagnosis and prevention of major birth defects and to promote international cooperation in combating them.

In its response, IF shared its concern about the use of prenatal diagnosis and selective termination of pregnancy as prevention measures. While this intervention may indeed reduce child morbidity and mortality, the birth defect itself will not be prevented. Instead, a prevention strategy which aims at eliminating children with disabilities, no matter how well-intentioned, can render the message that these children are regarded as "undesirable".

IF emphasized the importance of and need for primary prevention, through planned parenthood and the correct use of folic acid supplementation and food fortification with folic acid to prevent neural tube birth defects, such as Spina Bifida. IF stated that primary prevention also requires national education programmes to ensure that the right information reaches the whole population.

The WHO Resolution Birth Defects WHA63.17 was adapted to include increasing the coverage of prevention measures such as folic acid supplementation, and to urge Member States to continue providing care and support to individuals affected by birth defects.

The resolution also urges Member States to develop expertise and to build capacity on the prevention of birth defects and care of children with birth defects, to foster the development of parent-patient organisations and to support families who have children with birth defects and associated disabilities, and ensure that appropriate habilitation and support is provided to children with disabilities.

The Director-General was requested to support Member States in developing national plans for implementation of effective interventions to prevent and manage birth defects, including food fortification strategies.





Human Rights

Human Rights

Publication Equality in Healthcare (Eastern Europe)

In December 2010 IF published the booklet "This is a small story about life and death [Unfortunately, it is not a fairytale]". Life stories and images were gathered by IF President Pierre Mertens, IF board member Renée Höglin and IF communications officer Renée Jopp and developed into this special publication by writer Geerd Magiels and artist Bert Dombrecht. The storybook with a twist is an eye-opener to end the violation of rights of children with Spina Bifida and Hydrocephalus. In this day and age many children are still, in practice, denied those basic rights and fundamental freedoms that most people take for granted. Even in some places in Europe. Parliaments and parliamentarians have a key role to play in promoting and protecting human rights. IF urges them to promote and protect the rights of children born with Spina Bifida and Hydrocephalus all over the world. IF sent the booklet to Members of Parliament, politicians and other stakeholders, and distributed it during conferences.



Draft Position Paper Prenatal Counselling

In recent years new and improved methods of early diagnosis such as ultrasound have given parents the opportunity to learn about the condition of their baby before birth. Many expecting parents agree to an ultrasound examination without realizing that the findings could put them in a situation of urgent decision-making.



The unexpected diagnosis of a neural tube defect, such as Spina Bifida, is an extremely stressful experience for parents. In countries where abortion is an option, parents may need to decide on short notice whether to continue or terminate the pregnancy while they are still in a state of shock.

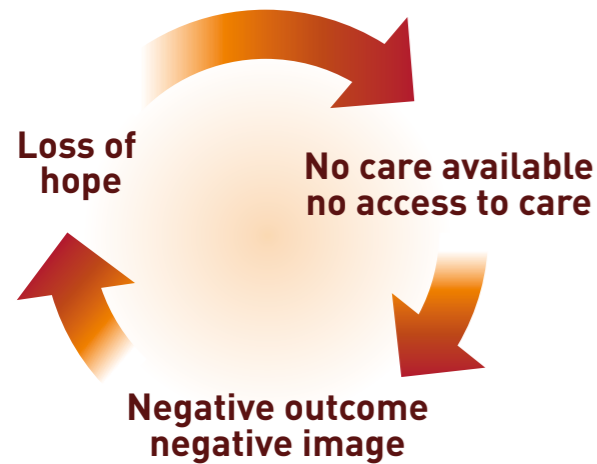
During the 1st European Congress on Prenatal Care and Prenatal Health in Brussels, Belgium, October 6-9, 2010, IF disseminated its Draft Position Paper Prenatal Counselling, with the support of the European Commission. Following the IF Resolution "Prenatal diagnosis and the right to be different", IF advocates for supportive and unbiased counselling. Health professionals should work with parent organisations to ensure that information is up-to-date, correct, and understandable for parents. The advice parents receive should never be dictated by negative stereotypes on disability.

Any explicit or implicit bias, practice or procedure in counselling that devalues the worth of the life of people with Spina Bifida and/or Hydrocephalus is a form of discrimination and is in breach of human rights principles and may be open to legal challenge.

International Solidarity

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 governmental bodies, service providers and society in general. The IF program for International Solidarity has been named: IF Child Help



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.

Without correct and timely treatment, the prognosis of children with Spina Bifida and/or Hydrocephalus is very poor. Their condition worsens, secondary disabilities such as blindness and cognitive impairment develop and children risk dying. The disastrous outcome of untreated and incorrect treated children 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 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)
- IF Child Help Belgium
- Schokland Foundation (Millennium Agreements), the Netherlands

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 Child Help 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 Kilimanjaro in cooperation with KCMC
- Tanzania, Dar es Salaam:** Association for Spina Bifida and Hydrocephalus Tanzania (ASBAHT)
- Tanzania, Arusha:** Arusha Lutheran Medical Centre (ALMC)
- Kenya, Kijabe:** Bethany Kids at Kijabe Hospital
- Zambia, Lusaka:** Beit CURE Hospital
- Malawi, Blantyre:** Queen Elisabeth General Hospital in cooperation with Beit CURE Hospital
- Sudan, Khartoum:** Khartoum Cheshire Home & the Spain Bifida Federal Association



Besides these official partners, IF Child Help 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, Paz Holandesa and GPDD.

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 Child Help and its knowledge network.



IF Child Help has been able to supply cost-efficient shunts to partners in the following countries:

- Africa** 1 Angola
- 2 Benin
- 3 Cameroun
- 4 DC Congo
- 5 Ethiopia
- 6 Ghana
- 7 Kenya
- 8 Malawi
- 9 Nigeria
- 10 Sudan
- 11 Tanzania
- 12 Uganda
- 13 Zambia
- 14 Zimbabwe
- Latin America** 15 Bolivia
- 16 Colombia
- 17 Guatemala
- 18 Haiti
- 19 Peru
- Asia** 20 Philippines

Numbers and achievements in 2010

Surgeries:

- 3,045 shunts delivered to 27 partners in 20 countries.
- 1,626 shunt operations performed by the projects.
- 593 ETV operations by CURE Hospital in Mbale, Beit CURE in Lusaka, Zambia, Queen Elisabeth Hospital in Blantyre, Malawi and Bethany Kids in Kijabe, Kenya.
- 475 SB operations performed by the projects.

Children in follow up:

- 12,594 children being followed in their rehabilitation and development.
- 2,691 children are actively participating in a continence management program.

Training:

- Annual workshop on Strengthening Parent Support Groups held in Dar es Salaam, Tanzania in July 2010: 24 participants from 9 countries.
- 23 trainings in continence management were organised for parents and their children.
- 49 trainings for parents were organised, other than on continence management.
- 12 trainings for youth with Spina Bifida and/or Hydrocephalus were organised.

Inclusion:

- 129 children gone to school as a result of proper continence management.
- Youth representatives are becoming more active in the support groups. Currently 23 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 89 schools are part of our local network.

Parent group building:

- 89 parent meetings were organised by the projects, attended by more than 3,600 parents.
- 6 new support groups were established.

Prevention:

- Around 410,000 Folic Acid tablets were distributed to approximately 2,400 women.

IF African Workshop 2010

Strengthening Parent Groups The road to sustainability

The IF African Workshop took place from 7 to 9 July 2010 at the White Sands Hotel in Dar es Salaam, Tanzania. The participants for the workshop came from Uganda, Kenya, Tanzania, Zambia, Malawi, Sudan, India, and Zanzibar; all were parents of children with Spina Bifida and Hydrocephalus (SBH) and represented the local parent support groups.

All the parent groups provided a brief presentation on the successes, challenges and future plans of their parent group. Next they all participated in a session on Leadership and Management, which covered areas like strategic planning, monitoring and evaluation, governance and sustainability. This included a situation and SWOT analysis which would later be used by parents while developing their plans for their groups. Using the Bridge model, the participants learned to identify in a three-step exercise where they were now, where they wanted to be and what was needed to reach their goals.

The IF African Workshop was organised simultaneously with the Pan African Pediatric Surgical Association (PAPSA) annual conference in order to enable the parents to share their concerns and ideas with the pediatric surgeons on the care of their children in the course of the week.

IF and PAPSA also organised a joint discussion on Quality of Life and Ethics, where a panel of parents, adults and surgeons openly spoke about and discussed their personal experiences. The panel consisted of Ms. Eli Skattebu (adult with Spina Bifida, Norway), Ms. Juliana Auma (Kenya) and Mr. Sam Wasike (Uganda), both parents of children with SBH, and pediatric surgeons Dr. Kachinga Schizinga (Zambia) and Dr. Santosh Karmakar (India). The discussion was led by Dr. Dan Poenaru, pediatric surgeon from Kijabe Hospital, Kenya, and Mr. Pierre Mertens, IF President.



Knowledge network

IF's motto is **"Knowledge is the key to a better life"**. Parents of a child, and adults, with Spina Bifida and/or Hydrocephalus, and professional care givers, need knowledge to make the right decisions and to seek and provide the proper treatment and care. The general population and governments need knowledge to prevent Spina Bifida and to respect and enforce the rights of persons with a disability.

The IF website and IF newsletters are an important means for IF to share knowledge and reach as wide an audience as possible.

IF board members participated in conferences and gave lectures to advocate for the prevention of Spina Bifida and to raise awareness about this condition. For instance, IF member organisations from Sweden, Norway, Denmark and Finland came together with top experts on Spina Bifida and Folic Acid in Stockholm during a Nordic meeting, on September 3-5, 2010. On December 18, IF's presi-

dent spoke at the first international workshop on research in foetal surgery in Milan, Italy.

In 2010 IF president Pierre Mertens also contributed to the book "Echo", about ultrasound and prenatal counselling.

Belgian weekly magazine Tertio published the article "Stereotypes kill babies with severe handicaps", featuring IF's Position Paper on the Groningen Protocol.

Volunteers are essential to the work of IF. IF relies on them for medical, legal and scientific advice and last but not least for the translation of documents and the IF website. IF continues to invest in the development of a volunteer network.

IF Annual Conference

Each year IF organises an international conference where all stakeholders can meet and receive and exchange information. In 2010 IF's 21st annual conference "What's the next step" was held jointly with Spina Bifida Hydrocephalus Ireland (SBHI) at the City West Hotel Dublin, June 11-12, 2010.

The conference was a great success and welcomed over 760 attendees from 17 countries. Mary McAleese, President of the Republic of Ireland, gave a thoughtful and inspiring opening speech, which touched and impressed all conference attendees. She emphasized the importance of ac-

tively working together to make sure that every bit of knowledge is shared and progress can be made.

A variety of topics was discussed during the educational sessions, from enhancing independence in adolescents with Spina Bifida to and bowel and bladder continence. IF President Pierre Mertens held a lecture during the annual conference, confronting the audience with the negative stereotyping of Spina Bifida and Hydrocephalus and the effects it has on prenatal counselling. IF medical advisor Dr. Benjamin Warf, associate professor Harvard University, gave a presentation about the cost-effective and successful treatment of Hydrocephalus through ETV (Endoscopic Third Ventriculostomy).

At the end of the first day of the conference Jan Ja ab, Regional Representative of the UN High Commissioner for Human Rights, delivered a speech in which he stressed the need to protect the rights of those born with Spina Bifida and Hydrocephalus.

Both days of the conference, young adults with Spina Bifida participated in special youth forums, discussing topics such as sexuality, relationships, continence issues, self image and day to day living. Separate sessions on similar topics were offered to adults with Spina Bifida. Chair of the youth forum was 27-year-old British actor David Proud, who was born with Spina Bifida himself. Chair of the adult forum was SBHI member Christy O'Neill, who at 60 years of age felt like a pioneer at living with Spina Bifida. IF board member Eli Skattembu was part of the panel, together with IF advisor Helen Healy, paralympic athlete John Fulham, and SBHI Continence advisor Frances Halligan.

The IF Award 2010 was presented to Dr. Timothy Brei by Mr. John Moloney, Minister for Equality, Disability and Mental Health, who also delivered the closing address of IF's international conference.



IF General Meeting

Prior to the 21st International Conference IF held its General Meeting 2010. IF President Pierre Mertens, IF Secretary General Lieven Bauwens and IF Board Member Teije Dijk presented IF's Annual Report 2009, IF's Financial Report, and discussed IF's future. Both Annual and Financial Report 2009 were adopted by the General Meeting (GM). Mr. Pierre Mertens was re-elected and entered his final term as IF's President. Mr. John Burke, Mrs. Renée Höglin and Mrs. Maria Cristina Dieci stepped down from the Board. The GM elected Margo Whiteford (Scotland), Erwin Calgua (Guatemala) and Eva Toft (Sweden) as new Board Members.



EU Workshop Capacity Building

In order to share experiences on primary prevention of neural tube defects and to build capacity for lobbying and campaigning, IF organised an intensive two-day workshop in Dublin for most of its European member organisations. IF members presented campaign and lobby activities that they were already engaged in and discussed how to further increase the impact of these efforts. During the workshop each participant committed to at least one individual lobby or campaign to guarantee concrete results of this meeting. The workshop was concluded with a joint session between the workshop participants and representatives from Bayer Schering Healthcare. Together they exchanged ideas on how to follow up the report "Act against Europe's most common birth defects" that IF and Bayer successfully launched in the European Parliament in January.

Expansion IF's membership

To reach as many people as possible IF is continuously looking for ways to expand its knowledge network. In 2010, during the General Meeting in Dublin, Ireland, four new members joined IF: Spina Bifida Association Queensland, Australia; Spina Bifida Association Aurora, Croatia; Fundación Amado Josue, Honduras; Spina Bifida Federal Association, Sudan.



From left to right:
Mrs. Eli Skattebu – IF Vice-president, Norway; Mr. Pierre Mertens – IF President;
Mrs. Mary McAleese – President of the Republic of Ireland;
Mrs. Thelma Cloak – IF board member, Ireland;
Mr. Fiach McDonagh – Chairman of Spina Bifida Hydrocephalus Ireland.

2010 IF Award 2010 - Dr. Timothy Brei



The IF Award 2010 has been awarded to Dr. Timothy J. Brei, Associate Professor of Clinical Pediatrics, Medical Director of the Spina Bifida Program at Riley Hospital Indianapolis, and Advisor to the Board of the Spina Bifida Association of America. Dr. Brei specializes in developmental paediatrics and has Spina Bifida himself. He received the IF Award for his work and research with adults and young adults with Spina Bifida and Hydrocephalus, for his committed involvement in the Spina Bifida community in the US and for being a role model for young persons with Spina Bifida and Hydrocephalus.

In 2010 Dr. Brei also co-edited a special issue of the journal *Developmental Disabilities Research Reviews: Spina Bifida - A Multidisciplinary Perspective* (Volume 16, issue 1), together with Dr. Jack M. Fletcher. The purpose of this special issue was to systematically review research on Spina Bifida within different domains in an effort to promote integration and awareness of this research across disciplines involved directly with Spina Bifida. The journal contained topics such as "Quality of life in individuals with spina bifida: A research update" and "Transition to adult health care for adolescents with spina bifida: Research issues".

Mr. John Moloney, Minister for Equality, Disability and Mental Health in Ireland handed the award to Dr. Brei at the closing session of the 21st Conference of the International Federation for Spina Bifida and Hydrocephalus in Dublin, Ireland.



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

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

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

Argentina

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

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

France

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

Australia

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

Colombia

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

Germany

Arbeitsgemeinschaft Spina Bifida und Hydrocephalus (ASBH)
Münsterstrasse 13
44145 Dortmund
www.asbh.de

Austria

Spina Bifida und Hydrocephalus Österreich (SB&HÖ)
Goldlackgasse 10
1220 Vienna
www.sbho.at

Croatia

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

Guatemala

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

Belgium

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

Denmark

Rygmarvsbrokforeningen af 1988
Hoptrup Kirkeby 11
6100 Haderslev
www.rygmarvsbrokforeningen.dk

Honduras

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



Ireland

Spina Bifida Hydrocephalus Ireland (SBHI)
Old Nangor Road
Clondalkin, Dublin 22
www.sbhi.ie

Italy

Federazione Associazioni Italiane Spina Bifida e Idrocefalo (FAISBI)
c/o Croce Verde A.P.M
Via San Vincenzo 25
20123 Milan
www.spinabifidaitalia.it

Associazione Spina Bifida Italia (ASBI)
Via Duomo 20
29020 Settima di Gossolengo (PC)
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/

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

Norway

Ryggmargsbrokk- og hydrocephalusforeningen
Brynsveien 96
N-1352 Kolsås
Norway
www.ryggmargsbrokk.org

Poland

Stowarzyszenie Chorych z Przepuklin Oponowordezeniow R.P. (ASBP)
ul. elazowej Woli 20/39A
20-853 Lublin
spinabifida.w.interia.pl

Peru

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

Asociación de Espina Bífida e Hidrocefalia del Perú (ASEBHIH PERÚ)
Av. La Capilla 1151, Dpto. 301
Rímac, Lima 25
www.asesbihperu.org

Portugal

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

Romania

Asociația Română de Spina Bifida și Hidrocefalie
Strada Secuilor Nr 7, Bloc B31, Sc.3 Et.2, Ap.38
Sector 4, Bucuresti
www.arsbh.ro/

Russia

Association of Spina Bifida and Hydrocephalus St. Petersburg
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

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

Spain

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

Associació Catalana d'Espina Bífida i Hidrocefàlia
Sorolla 10, Baixos
Barcelona 08035
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

Switzerland

Schweizerische Vereinigung Spina Bifida und Hydrocephalus (SBH)
Rue du Joliment 22
2525 Le Landeron
www.spina-hydro.ch

Turkey

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

UK

Association for Spina Bifida and Hydrocephalus (ASBAH)
42 Park Road
GB-Peterborough PE1 2UQ
www.asbah.org

USA

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



Financial result in 2010

Statement of the auditor

Report of the auditor on the financial statements for the year ended 31-12-2010 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 31-12-2010, prepared under the responsibility of the board of directors of the federation, which show a balance sheet total of € 408.377,18 and a profit for the year of € 5.805,84.

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 31/12/2010 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 29th 2011

BVBA De Nul & co
bedrijfsrevisor
Auditor

represented by
Roger De Nul



Balance sheet at 31 December 2010

Assets	31-Dec-10	31-Dec-09
Tangible assets	6.089,82	2.697,49
Investments	11.965,74	8.757,89
Depreciations investments	-9.268,97	-6.591,19
Office furniture	3.577,83	0,00
Depreciations office furniture	-715,57	0,00
Cautions	530,79	530,79
Amounts receivable	145.780,12	145.780,12
Customers	36.067,41	117.714,12
Subsidies to receive	25.000,00	25.000,00
Others to receive	1.132,00	3.066,00
If child help current account	54.278,31	0,00
Bank & cash accounts	278.421,25	301.077,78
Stocks	0,00	20.133,40
Bank accounts	278.421,25	280.944,38
Transit accounts	7.388,39	13.837,58
Costs for next year	13.837,58	13.837,58
Profits for this year	36,16	0,00
Total assets	408.377,18	463.392,97

Liabilities	31-Dec-10	31-Dec-09
Reserves	260.282,63	254.476,79
Funds of if	254.476,79	294.063,02
Profit-loss bookyear	5.805,84	-39.586,23
Amounts payable	75.300,61	85.092,27
Kbc - accounts	0,00	72,46
Suppliers	34.387,57	53.112,72
Taxes to be paid	574,00	839,00
Salaries to be paid	1.295,84	1.569,82
Provision holiday fee	14.361,42	10.038,10
Projects current accounts	24.681,78	19.280,83
If child help current account	0,00	179,34
Transit accounts	72.793,94	123.823,91
Profits for next year	72.793,94	123.823,91
Total liabilities	408.377,18	463.392,97

Profit and loss 2010

OUT

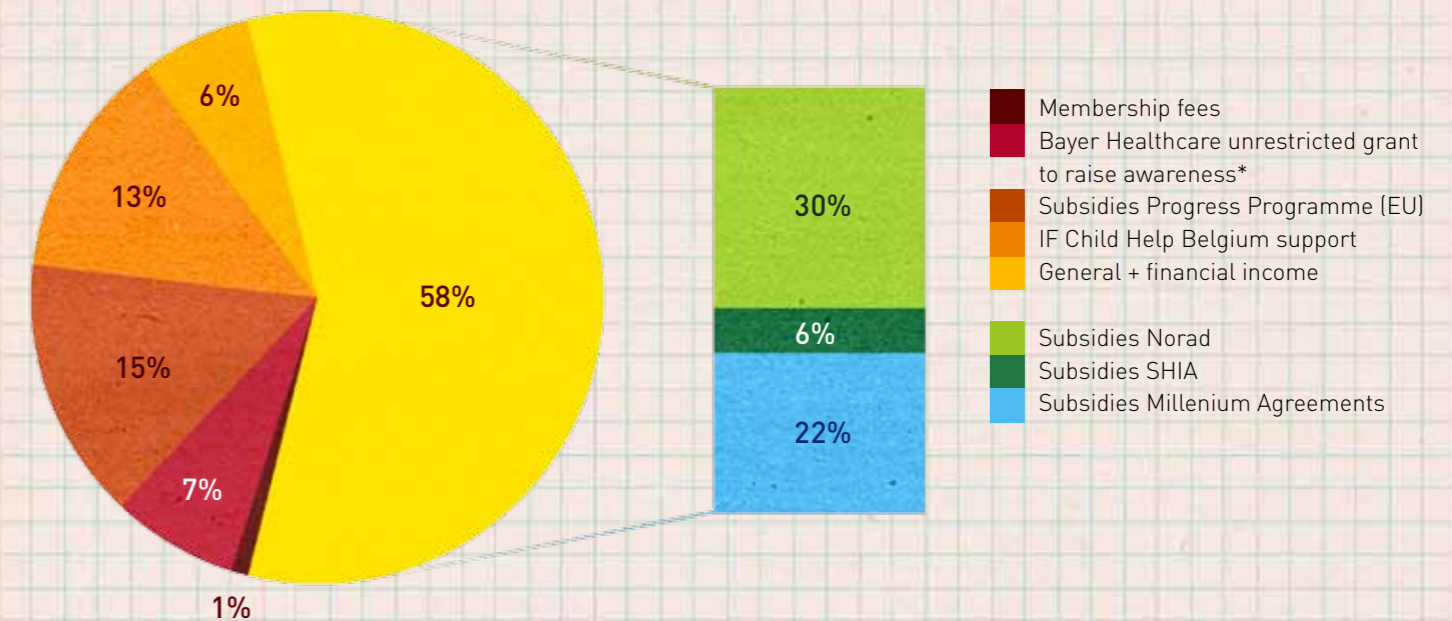
Diverse costs	643.364,17
Housing costs	13.865,22
Office supplies	4.499,94
Publications - copy	18.240,75
Communication costs	5.713,65
Membership fees	470,00
Fee bookkeeper	3.844,29
Fee auditor	1.542,75
Fee Management Consulting	4.840,00
Other fees	71.832,94
Insurance	977,11
Transport expenses	102.740,75
Official documents (visas)	35,86
Representation	26.282,23
Medical material projects	108.693,85
Salaries in projects	86.550,55
Training projects	23.084,43
Other expenses projects	49.682,86
Conferences - meetings	120.466,99
Salary costs	197.955,35
Salary costs	197.955,35
Depreciations	3.393,35
Depreciations	3.393,35
Financial costs	3.161,38
Financial costs	3.161,38
Exceptional costs	542,17
Exceptional costs	542,17
Total costs	848.416,42

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General income	841.260,67
Membership fees	8.340,00
Bayer Healthcare unrestricted grant to raise awareness*	61.000,00
Subsidies project Norad	259.477,64
Subsidies project SHIA	54.110,30
Subsidies project EU-project	125.000,00
Subsidies project Millenium Agreements	153.543,02
Matching funds Millenium Agreements	29.867,12
IF Child Help Belgium support	109.710,57
Recuperation salary costs	1.792,05
Diverse recuperation	38.419,97
Financial income	12.961,59
Financial income	12.961,59

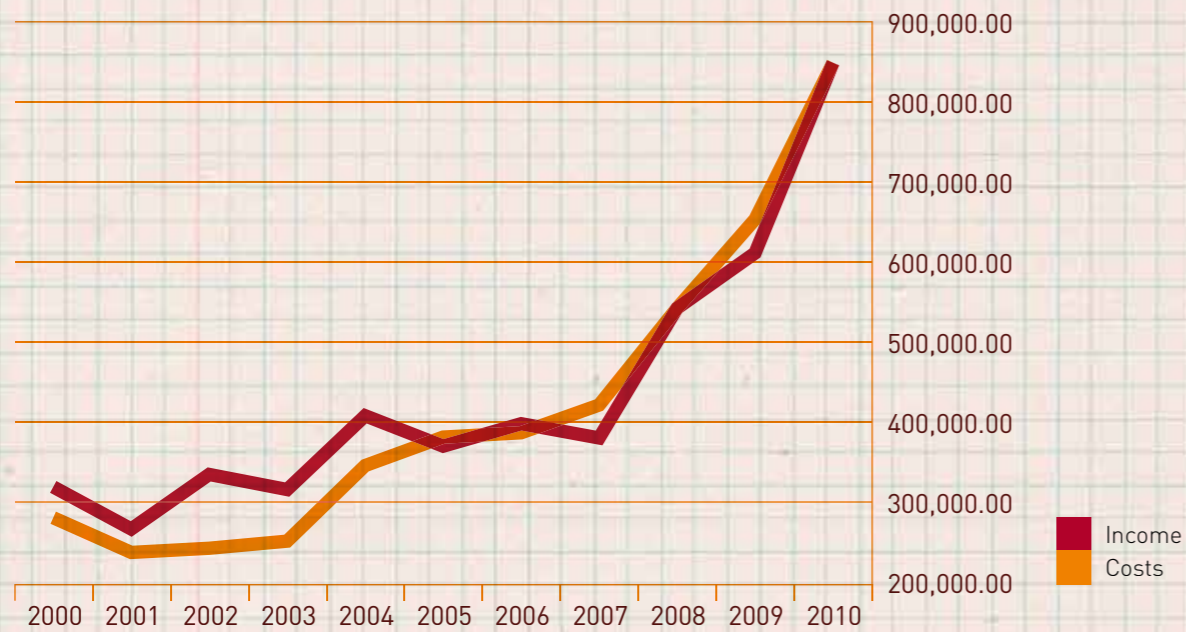
Total income	854.222,26
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Result	5.805,84
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*IF thanks Bayer Healthcare for their in-kind contribution for the NTD prevention campaign in Europe, for details check www.bayerpharma.com/en/corporate_responsibility/access_to_medicines/joint_efforts/patient_organizations

Historical Perspective



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



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

Cellebroersstraat 16 - 1000 Brussels, Belgium

Tel. +32 (0) 2 502 04 13 Fax +32 (0) 2 502 11 29

info@ifglobal.org – www.ifglobal.org



**INTERNATIONAL
FEDERATION
for
SPINA BIFIDA
and
HYDROCEPHALUS**