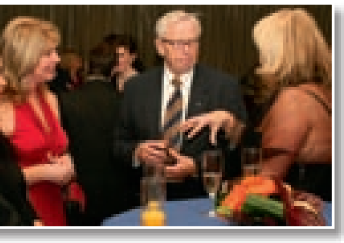
INTERNATIONAL
FEDERATION
for
SPINA BIFIDA
and
HYDROCEPHALUS

Consultative status special category with the Economic and Social Council of the United Nations, Participatory status, Council of Europe



Annual Report 2008

Drawing Smiles

Presented on the General Meeting of

The International Federation
for Spina Bifida and Hydrocephalus

30 June 2009

Swan and Dolphin Resort,
Orlando, USA

IF ivzw

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

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Patroness of IF is Her Imperial and Royal Highness
Princess Astrid of Belgium

Table of Contents

Annual report 2008: Introduction

It is definitely in Vietnam that I learned that a smile is a gift, a precious present from one person to the other. By smiling at somebody you automatically draw a smile on their face too.
In 2008, IF contributed to the training of 2 Vietnamese neurosurgeons in the technique of endoscopic surgery to treat Hydrocephalus without shunting. This was a unique cooperation between the Cure Children's Hospital in Mbale (Uganda), Handicap International (Belgium) and IF in the IF-CURE international Programme to Advance the Treatment of Hydrocephalus (iPATH).

For the past 30 years many people have been involved in IF's worldwide network of knowledge on Spina Bifida and Hydrocephalus in the developed world and in the developing countries. We have met hundreds of people with these conditions and worked together with them. In these years I had and still have a lot of fun and meet smiles all the time. Even though we are working for and with persons with severe disabilities I rarely see tears or sadness. Parents, children and adults all over the world try in a positive way to make the best of their lives. Why do we perceive more happiness in this work than in other places? Why are we smiling more than others?

Research in the Netherlands and Norway, Kenya and the US has shown that young adults with Spina Bifida rate their quality of life higher than the control group of youngsters of their age without an impairment. We have fewer depressions and more smiles in our network than in the control group without a disability.
Strange, because is it not the expected poor quality of life that is the reason to promote prenatal selection? The sadness is coming from outside, from a society that finds it difficult to cope with differences.
For his outstanding research on the quality of life of newborns with Spina Bifida Dr. T.H.R. de Jong from Rotterdam received the 2008 IF Award.

The Portuguese association, organisers of our 2008 annual conference with the theme 'Drawing Smiles - Towards Adulthood' wanted to correct the negative perception which surrounds Spina Bifida.
Our Portuguese friends put together a very diverse programme including drawings, two photo exhibitions, music, dance performances and jokes. One exhibition showed black and white photos revealing the beauty of our bodies, the other was an exhibition of smiles made by Zjuul Devens, who is the home photographer of IF. The starting point of the conference was the question: "How can we educate our children to become happy adults?"

To believe in the future of our children is important and that is why the 2008 IF African workshop had the theme 'Parental Hope'. This activity also focused in a positive way on the non-medical aspects of living with the conditions.

In 2008 the IF network built further on the two major elements of its mission, "the right to live a full and decent life with all our differences" and "primary prevention." IF made major steps towards fortification of staple food in Africa. In a well attended workshop on Flour Fortification IF members were trained to become advocates in their countries. The cooperation with the Flour Fortification Initiative (FFI) resulted in successful application for obtaining a grant for a programme to train health officials and millers in Africa to implement fortification in their countries.

On the first of December 2008 IF celebrated the start of its 30th anniversary year with a concert and dinner in the presence of Princess Astrid of Belgium.

Reading all this should draw a big smile on your face.

I hope you keep smiling as you read on.

Pierre Mertens
IF President


EXAM LAMP ON
POWER ON
SKIN/MANUAL CONTROLLER
36.8
37.0
RADIANT HEAT WARMER
CAUTION
NO NAKED FLAME
NO SMOKING
PROBE
HUMIDIFIER

2008 Through the Eyes of Protagonists

Major Achievements aimed at preventing Spina Bifida and Hydrocephalus and improving the quality of life for those with Spina Bifida and Hydrocephalus

IF as an Organisation

IF Child Help Belgium started fundraising in Belgium
Agreement with the European Commission on representation of people with Spina Bifida and Hydrocephalus

Prevention

Close cooperation with FFI
Prevention workshop in Lisbon, Portugal
Development of a advocacy toolkit on Prevention

Human Rights

Partnering with the European institutions as NGO representing people with Spina Bifida and Hydrocephalus
Increasing recognition in Italy

Development Cooperation

Over 3,000 surgeries, over 6,000 children in follow-up
4 neurosurgeons trained in the IPATH programme
IF African Workshop 2008 on Parental Hope and Inclusion

Knowledge Network

Two new members (Algeria, Romania)
Successful conference in Portugal
Development of volunteer network
30th Anniversary dinner

Financial Stability

Achieving EU funding for 2008 onwards
Tax deductibility IF Child Help
Continuing private donor support
Pilot action with member (ASBAH)

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
Mrs. Renée Höglin, Sweden
Mr. Luis Quaresma, Portugal
Mrs. Thelma Cloake, Ireland
Mrs. Maria Cristina Dieci, Italy

Mrs. Thelma Cloake, Mr. Teije Dijk, Mr. Pierre Mertens, Mr. Jon Burke, Mrs. Eli Skattebu, Mrs. Karin Björk (In lieu of Mrs. Renée Höglin), Mr. Douglas Sorocco, Mr. Luis Quaresma. Not pictured : Mrs. Renée Höglin, Mrs. Maria Cristina Dieci.

The board met in person in June and October 2008.

Staff

Brussels office:
Mr. Lieven Bauwens, General Coordinator
Mrs. Els De Clercq, Coordinator Development Cooperation
Ms. Hilde De Keyser, Policy Officer Prevention
Mrs. Renée Jopp, Communications Officer
Mr. Cosmas Taabazuing, Administrative assistant

Kampala Office:
Mrs. Rebecca Nakitto Sagabo, Administrative assistant – East-Africa.
Mrs. Olivia Nakato, Policy Officer Human Rights

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. Through the Progress-programme, it holds a privileged relationship with the European Commission.

IF is a founding member of IF Child Help Belgium (11 September 2006), focussing on Development Cooperation. IF is part of the Leaders Group of the Flour Fortification Initiative (FFI), and a member of and the Belgian Disability and Development Cooperation initiative "één op tien" ("one in ten").

The president holds board memberships of the European Disability Forum (EDF), Bo Hjelt Foundation, Flemish Spina Bifida and Hydrocephalus Association and is a member of the General Assembly of CBM Belgium.

Members of the board held several lectures worldwide on the topic of Human Rights and Prevention. Among others, they lectured in Belgium, Denmark, Italy, Slovakia and Portugal.

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

In 2008, board members participated actively in the representation of IF by attending several conferences, such as the European Commission's seminar "Active Players in the Internal Market" and EDF's General Assembly.

IF Consultative Team

Prof. Dr. Lieven Annemans, Health Economics
Mrs. Sofie Blancquaert; legal and ethics consultant IF, lawyer Chemiphar
Dr. Jan Cordonnier and Mrs. Annick Uytterhaegen, laboratory
Mrs. Maria-Helena –Myleen- Christiaens, consultant continence management
Dr. Filippo Ciantia, tropical medicine
Mr. Zjuul Devens; multimedia, photography and camera work
Dr. Guy De Groot; Folic Acid working group Belgium
Prof. Dr. Patrick De Vlieger, anthropology and disability
Dr. Philippe Gillis, consultant paediatrics and tropical medicine
Mr. Bo Hjelt, consultant fundraising and general management
Prof. Dr. Emmanuel Keirse, user counselling
Dr. Martina Oneko; medical consultant IF, consultant paediatrics/neuro-paediatrics
Prof. Dr. Glen Maberly; Flour Fortification Initiative
Dr. Joe Mulinare; prevention expert, Centers for Disease Control and Prevention
Mr. Koen Sevenants, senior advisor Development Cooperation Asia
Prof. Dr. Regine Steegers-Theunissen, Professor in Reproductive Epidemiology
Mrs. Vero van den Abeele; consultant IF Knowledge Network
Mr. Dirk Van Den Steen; consultant Health Economics
Mrs. Marjan van Mourik; management and fundraising consultant IF
Mrs. Annie Van Thienen; Mr. Eric Holdtgrefe; Mrs. Teresa Cole; translator
Dr. Carla Verpoorten; medical consultant, neuro-paediatrician
Dr. Anna Verster; senior consultant Flour Fortification Initiative
Andrew Russell; senior advisor flour fortification
Dr. Benjamin C. Warf; medical consultant, paediatric neurosurgeon, ABNS, ABPNS
Dr. Richard Bransford, general surgeon, MD, FACS
Mr. Donald Willemsen; Ms. Sofie Van Houtte; Annie Van Thienen, user representation
Frank De Graeve; communications advice,
Joris Petillion; commercial advice
Ludo Longin; DCS

Prevention

Flour Fortification Initiative

The Flour Fortification Initiative (FFI) is a network of individuals and organisations working together to make flour fortification standard practice in large roller mills worldwide so that people will benefit from essential nutrients, such as Folic Acid, zinc, iron, vitamin B12 and vitamin A. The network includes representatives from private, public and civic organisations who combine their resources to foster mandatory flour fortification.

In June 2005, the General Assembly of IF agreed on a policy statement, supporting mandatory flour fortification and calling for action to promote the health benefits of Folic Acid throughout the world. Thereafter, IF became an active member of the Leaders Group of FFI, to ensure that Folic Acid is added to the formula of the flour.

The situation on flour fortification in the various countries in the world looks very different. Whereas the Americas all have mandatory fortification of wheat and/or maize flour, Europe appears to be a blank spot on this map. There are active debates in several European countries, especially on the food safety aspects of fortified flour. At this moment, the United Kingdom fortifies flour with iron, but not Folic Acid. No other European country implements mandatory flour fortification while many countries around the world have years of experience in this regard.

In recent years the European Commission issued some important policy documents on food safety and supplementation of vitamins and minerals to food. It is important to keep this information in mind while advocating for flour fortification. Folic Acid is one of the vitamins allowed by the European Commission to be added to staple foods. The World Health Organisation (WHO) has adopted guidelines for fortifying flour with Folic Acid, iron, zinc, vitamin B 12, and vitamin A. This is an important step in the implementation of flour fortification.
Flour fortification can only become common practice when we adopt a multi-stakeholder approach and work together towards the same goal. Therefore it is important to contact authorities, millers, scientists, and others committed to improving the lives and futures of people in their country.

In 2008, nearly 100 leading nutrition, pharmaceutical and cereal scientists and milling experts from the public and private sectors from around the world gathered for four days to harmonize advice for countries considering national wheat and/or maize flour fortification. The report of this workshop has become a guiding document adopted by the WHO. "Recommendations on wheat and maize flour fortification. Meeting Report: Interim Consensus Statement. Geneva, World Health Organisation, 2009", is an essential document in advocacy efforts for flour fortification.

Resources

Flour Fortification Initiative: **http://www.sph.emory.edu/wheatflour/index.php**

IF Workshop Flour Fortification

During the 2008 annual conference in Lisbon IF members attended a special workshop on flour fortification. They received training and resources which will enable them to advocate for flour fortification with Folic Acid in their countries. Following the IF Policy Statement on Prevention of Neural Tube Defects and Mandatory Food Fortification (2005) IF and its member organisations continue to call on all countries to fortify staple food with the vitamin Folic Acid to reduce the incidence of neural tube defects (NTDs).

Resources

Toolkit for flour fortification in Europe

Human Rights

IF Award 2008

The IF Award 2008 is given to Dr. T.H.R. de Jong, paediatric neurosurgeon, in recognition of his scientific contributions concerning the debate on active euthanasia and his critical comments and publications on this issue. He has published a scientific paper covering pain and unbearable suffering in babies with Spina Bifida. His thesis: children with Spina Bifida are not suffering unbearably and pain can be managed. Dr. De Jong stresses that, although people with Spina Bifida and Hydrocephalus have many of issues to deal with, every time he sees a child with Spina Bifida and/or Hydrocephalus, he sees a normal human being with problems, just like he himself has problems.

Dr. De Jong was, and still is, angered by the medical nonsense that is told about Spina Bifida and Hydrocephalus. The parents receive a picture of their newborn which is absolutely negative and incorrect. Presenting the consequences of Spina Bifida in such a pessimistic way, creates an incorrect and narrow-minded image of this neural tube defect. As a result, many parents opt for life-termination. During the IF conference in Lisbon he gave an overview of children in his clinic. Even the most severe form of Spina Bifida does not make the child suffer. Dr. De Jong has researched the issue of pain in newborns with Spina Bifida, concluding that when the baby suffers from pain, it can be alleviated easily. The criteria used in the Groningen protocol are incorrect, it is incompatible with human rights and it is unclear in whose interest these decisions are made.

IF Vice-President Eli Skattebu hands over the IF Award 2008 to Dr. Rob de Jong

Deliberate termination of life of newborns with Spina Bifida, a critical reappraisal

by Dr. T. H.R. de Jong

Some years ago, Verhagen et al. (2005, 2006) presented the so-called 'Groningen Protocol', a protocol meant to be used in cases of active termination of life of newborns, eg newborns with a severe form of Spina Bifida. According to Verhagen et al., deliberate termination of life can be necessary because of the presence of "unbearable and hopeless suffering, acutely and long-term, with no other proper medical means of alleviating the suffering". For the public prosecutor, the termination of life is acceptable if four requirements are properly fulfilled: (1) the presence of hopeless and unbearable suffering, (2) consent of the parents to termination of life, (3) consultation of another physician or of a multidisciplinary MMC team, and (4) a proper and careful execution of the termination itself. These four criteria are the cornerstone of the Groningen Protocol, which was approved and adopted by the Dutch Association of Paediatrics in 2005.
In 2005 Verhagen et al. published an article in the leading Dutch medical journal where they presented 22 cases of active life-termination of newborns; all appeared to be cases with Spina Bifida. The motivation for the judgement of 'unbearable and hopeless suffering' (and therefore for life-termination) in these 22 cases of Spina Bifida was:

1. 'suffering' (acute and chronic pain, physical pain) (100% of the 22 cases);
2. the 'lack on ability to live or do things independently' as the result of 'severely disturbed sensomo toric development' (100% of the 22 cases);
3. the 'lack of possibility to verbal and non-verbal communication' (82% of the 22 cases);
4. 'the prospect to dependency to the medical circuit as the result of frequent hospital admissions and operations' (77% of the 22 cases)
5. the 'life expectation' ('the burden of severe suffering increases by a longer life span') (in 59% of the 22 cases).

Regarding this concept and practice of life-termination of new-borns with Spina Bifida the following statements are made / conclusions are drawn:

a. There is no evidence that newborns with MMC and Hydrocephalus do either 'suffer' unbearably or hopelessly and certainly not without the prospect to relieve this suffering by standard care. 'Suffering' itself is a non-conclusive, and in newborns, inapplicable denominator that should not be used anymore. Although they will in their future life be confronted with handicaps, sometimes very severe, their future prospects and their actual experienced quality of life cannot be predicted with such certainty at birth that their lives can be regarded as hopeless or meaningless ('quality of life judgments' as such being unacceptable in this decision making). Possible discomfort in these newborns can easily be treated in a straightforward way by active treatment (closure of the defect and shunting the Hydrocephalus) and, when necessary, by the use of a professional pain/symptom protocol.
b. The decision not to treat such a newborn, when based on expected handicaps, possibly violates the 'non-discrimination' principle (Dorscheidt, 2006). When not being treated, they are not terminally ill because of the MMC and/or Hydrocephalus per se; they are 'terminally ill' because of this non-treatment decision. Not being terminally ill, it is not 'humane' or 'merciful' to terminate their life, this also being not in accordance with international legislation and international medical recommendations.

c. When untreated and when it is the intention to alleviate actual discomfort (this question of intent being crucial to a moral and legal analysis of end-of-life decisions including active termination of life), this can always be achieved in an effective way by using one of the widely accepted palliative protocols. Such a child can and should be cared for in a respectful and dignified way, providing all its actual needs (which apparently is not death itself). This being the case, there is no indication whatsoever for the deliberate termination of the life of children born with MMC. The needs of these untreated newborns are the same as the needs of all newborns: proper care, feeding, comfort, respect and love; till death (and apparently not death itself). The 'need' for life termination in these patients can only be regarded as an indication of insufficient palliative care.

d. While Verhagen et al. (2005, 2006) must be credited for bringing the discussion about deliberate termination of newborns in the open, to date, there does not seem to be much in their qualifications that can be quantified properly, especially not in cases of MMC, which is prone to quality of life judgments (and thereby neglecting the needs and rights of the newborn). To date, the Groningen protocol, therefore, cannot be regarded as very useful. Being a tool, it seems to have been changed in a means in itself. To gain more usefulness, at least it has to be extended in a way as proposed by Dorscheidt (2006), by adding charts such as the Comfort Score and the VAS and by adding palliative medication charts. Thus, it should be changed from a doctor-centered protocol to a patient-centered protocol.

e. To throw more light on these end-of-life decisions, Verhagen et al. should extend their retrospective study, focusing on the medical aspects of the 22 cases. Thus, it must be possible to get a basic understanding of the extent of the malformations themselves, of possible co-morbidities, whether or not quality of life judgments were made, how 'unbearable suffering' was ascertained, how palliative care was offered, and why this failed. Such a study would contribute significantly to the open discussion they propagate. Verhagen is undoubtedly correct indeed in his appeal: "It's time to be honest about the unbearable suffering endured by newborns with no hope of a future".

f. Finally, to date it remains unclear on what grounds the Dutch Association of Paediatrics has adopted the Groningen protocol and why international legislation, international human rights instruments, and international medical recommendations appear not to hold for the Netherlands, especially not in newborns with MMC.

UN Convention on the Rights of Persons With Disabilities

In 2008 the UN International Day of Persons With Disabilities focused attention on the "Convention on the Rights of Persons With Disabilities". Through the European Disability Forum IF was actively involved in the preparation of this convention, including the right to life and the right to all available treatment and care that can improve the quality of life of persons with a disability.

The convention has now been signed by 142 member states, but the Holy See is not one of them and will not be if the wording "reproductive health" is not changed. In some countries reproductive health services include abortion. According to the Holy See, the convention leaves the door open to aborting unborn children because of their disabilities. Protecting the rights, dignity and worth of persons with disabilities remains a major concern for the Holy See.

Open letter to Pope Benedict XVI

IF president Pierre Mertens wrote a letter to Pope Benedictus XVI, stating that IF shares the Holy See's concern about the systematic elimination of unborn and newborn children with a disability. In the letter he also explains why IF supports the UN convention and IF's interpretation of the questioned paragraphs referring to IF and EDF resolutions on "Prenatal Diagnosis and The Right to be Different" and "Active termination of life of infants with impairments and the right to live".
IF and its member organisations continue to advocate for equal rights, treatment and inclusion of persons with disabilities.

"IF is supporting the UN convention because IF reads articles 23, 25 and 10 with a spirit as mentioned above as follows:

Article 23(b) seeks to highlight and emphasize the right of persons with disabilities (both men and women) to freely decide the number and spacing of their children.
In other words, it makes mention of the fact that consenting spouses with disabilities have a right to receive appropriate information relating to family planning methods and the right to participate in reproductive health services such as intake of folic acid to prevent neural tube defects such as spina bifida.

Article 25(a) of the Convention, IF understands that persons with disabilities are guaranteed the right to the enjoyment of the highest attainable standard of health on an equal basis with others without discrimination on the basis of disability. In this regard, States Parties are mandated to provide persons with disabilities with the same quality of affordable health care as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes.

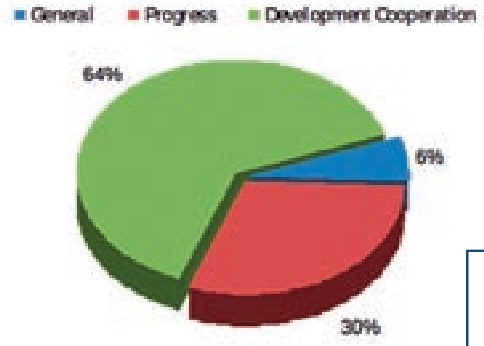
The wording of Article 10 implies that the unborn child's right to life is protected when it reaffirms that every human being has an inherent right to life. This includes unborn children for those who are in agreement with the concept that human life begins at conception. The practice of prenatal diagnosis in some countries resulting in more than 95% of the cases with spina bifida being aborted shows that in general medical philosophy no longer accepts this concept."

Development cooperation

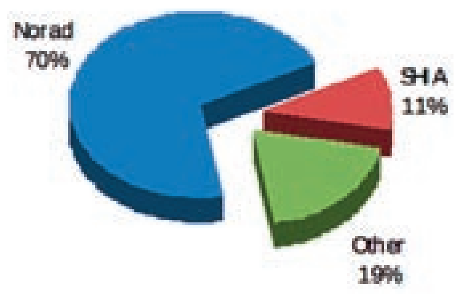
IF facilitates solidarity between persons with Spina Bifida and Hydrocephalus all over the world. Knowledge transfer in all directions made IF the worldwide expert on Spina Bifida and Hydrocephalus.

Thanks to the partnership with Ryggmargsbrokk- og hydrocephalusforeningen (Norway – RHF) and Riksförbundet för Rörelsehindrade Barn och Ungdomar (Sweden - RBU) that has the support of the Norwegian and Swedish governments (respectively via NORAD through Atlas and SHIA), IF has been able to develop, with the help of reliable local partners and INGO's, a comprehensive package for treatment and rehabilitation of children with Spina Bifida and Hydrocephalus in six African countries. In 2008, support has been expanded through ASBAH from the UK, the Mantana Grant and the Schokland Foundation from the Netherlands.

Division of Income



Development Cooperation



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

- Improve the basic local conditions for the treatment and rehabilitation of children with Spina Bifida and Hydrocephalus by organising appropriate training at all levels.
- Empowerment of groups of people with Spina Bifida and Hydrocephalus in the South.
- Social inclusion of people with Spina Bifida and Hydrocephalus in the South 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 persons with Spina Bifida and/or Hydrocephalus.
- Research on the causes and incidence of Spina Bifida and/or Hydrocephalus in developing countries.
- Primary prevention in developing countries.

The official partners in the 6 African countries where IF works are:

- Tanzania, Dar es Salaam: CCBRT Disability Hospital
- Tanzania, Moshi: CCBRT Kilimanjaro in cooperation with KCMC
- Kenya, Kijabe: Bethany Kids at Kijabe Hospital
- Uganda, Kampala: Katalemwa Cheshire Homes (KCH)
- Uganda, Mbale: Cure Children's Hospital Uganda
- Zambia, Lusaka: in 2008, the partnership changed from CBR Lusaka to BEIT CURE Hospital Lusaka
- Malawi, Blantyre: Queen Elisabeth General Hospital
- Sudan, Khartoum: Cheshire Homes
- A new partner since 2008 is: Uganda, Mbarara: OURS

Besides these official partners, IF has a wide network of partnerships with International NGO's, NGO's in the South and other foundations, enabling us to reach and work for our target group, being children and adults with Spina Bifida and Hydrocephalus: CURE, Lilianefonds, CBM, AVSI, Handicap International, Bethany Relief and Rehabilitation, Cheshire Homes, Paz Holandesa and GPDD.

On medical and scientific level, IF has links with, among others, FIENS (Foundation for International Education in Neurological Surgery), COSECSA (The College of Surgeons of East, Central & Southern Africa), PAACS (Pan-African Academy of Christian Surgeons), PAPSA (Pan-African Paediatric Surgical Association,) Madaktari Africa and several Universities and Medical Schools in the South.

Numbers and achievements in 2008

Surgeries:

- 1850 shunts delivered to different partners. 1704 shunt operation, including revisions, in the different projects
- 501 ETV-operations in Mbale, Uganda; Lusaka, Zambia and Kijabe, Kenya.
- 648 Spina Bifida operations (closure of the myelomeningocele and others)

Children in follow-up:

- Total amount of children followed (covering all years of cooperation): 6236 children with Hydrocephalus only and 3272 children with Spina Bifida (with or without Hydrocephalus)
- 936 children are in CIC follow-up, more than 5000 catheters have been distributed and more than 500 capsules of oxybutinine have been distributed
- 476 children are in bowel management follow-up and received a cone

Training:

- different training initiatives for professionals (ranging 1 day to 3 months), in total 615 people reached
- Annual workshop on parental hope and inclusion in Arusha, Tanzania: 37 people from 11 different countries attended
- Continence Management: 286 parents attended a CIC workshop or training initiative

Inclusion:

- 169 children reported to be in school as a result of the programme and specifically the continence management programme
- Annual workshop focusing on inclusion with expanded network on the topic of inclusion and inclusive education

Association building:

- Functioning parents groups in all 6 African countries
- 79 different parent meetings in the IF projects, reaching over 2647 parents
- Empowerment of parents through training, education and exchange

Prevention:

- 4041 mothers seen through the projects received free Folic Acid tablets
- Prevention of kidney infections and renal damage through the continence management
- Prevention of further damage through early treatment of Hydrocephalus
- Established networks in the area of micronutrients and food fortification

The iPATH programme

Together with Dr Ben Warf, CURE International and the Karl Storz Company, IF developed an achievable neurosurgical programme for the treatment of Spina Bifida and Hydrocephalus:
the **I**nternational **P**rogramme to **A**dvance the **T**reatment of **H**ydrocephalus (iPATH).

This training programme transfers the results obtained in Uganda and trains and equips neurosurgeons responsible for treating Hydrocephalus in developing countries.

Experience in Uganda has demonstrated that, in the setting of an emerging country, the majority of children with Hydrocephalus can be adequately treated using endoscopic methods. In young infants, our experience was similar to that of others, in that ETV alone was not effective in avoiding shunt dependency for the majority. But it has been demonstrated that choroid plexus cauterization in combination with endoscopic third ventriculostomy (ETV/CPC) was extremely effective . The ETV/CPC technique requires the use of a flexible fiberoptic endoscope in order to access the choroid plexus throughout both lateral ventricles.

The CURE Children's Hospital in Mbale, Uganda, provides the high volume of patients necessary to master these techniques in a relatively short time. In 2 months, a trainee can expect hands-on training in 50 to 100 ETV/CPC procedures.

The goal of iPATH is to develop a network of hospitals throughout the world that are competent to offer this treatment option and thus avoid the dangerous problem of shunt-dependence, especially for children in economically depressed regions. An additional goal is to develop a database of information through this network in order to improve on our ability to treat this common condition.

Through joint efforts, 4 neurosurgeons have been trained in 2008 in the iPATH programme:
Dr. T. Dakurah from Ghana and Dr. R. Hamid from Bangladesh and Drs. Nguyen en Minh from Vietnam.

IF designed a separate website section on neurosurgery and the iPATH programme on
http://www.ifglobal.org/en/neurosurgery.html

Koen Sevenants (left) and Pierre Mertens (right)

Giving each other hope!

By Eli Skattebu, IF Vice-president

People with Spina Bifida and/or Hydrocephalus form a new group in our population. The reason is the invention of the shunt, at the end of the 1960's, that made it possible for children with Hydrocephalus to survive.

Children have, so far, been the largest group of people in the developing programme of IF, but little by little we got to know a small group of young adults. These people and their families have, as the oldest generation, their own experiences that the younger children and their parents would like to hear about.

Francesca

At the Bethany Kids Hospital in Kijabe, Kenya, they have seen the need for this kind of exchange of experiences, and have appointed Francesca, who has Spina Bifida. Her job is to activate the children who are admitted to hospital and to meet families who have children with Spina Bifida and/or Hydrocephalus. Her own story is a strong statement, characterized by the lack of knowledge of the diagnosis among the health service as well as the society. But today Francesca is a newly married and working woman. At the hospital she does a fantastic job with the children and by sharing her own story with the families with children with Spina Bifida and/or Hydrocephalus, she gives them hope for the future.

At the workshop in Tanzania, in autumn 2008, the participants also took part in a meeting of the parent group in Moshi. While the parents held their meeting, Francesca took the initiative to gather the children for games and talks.
Quickly the children confided in her and when she told them that she had Spina Bifida herself and showed them her braces, the children were pleased to show her their braces and feet. Francesca asked them about their problems with incontinence, and she happily shared her own experiences, to the great admiration of the children.
Because she has her own experiences, this became a different conversation than if it were professionals asking questions, because they have a more clinical approach to these questions.

The building up of parent groups is one of the goals for the aid programme of IF and in these groups young adults also become important participants. By gathering the families together they have opportunities to meet other families in the same situation and receive information about the diagnosis. In the long term we hope they will become associations that can also work on matters of concern to the group.

The parent groups in Africa and the associations in the European countries that contribute to the aid programme of IF, have experiences that ordinary developing-workers do not have and that becomes very important when you have a relatively new and rare diagnosis. Their exchange of experiences is useful for the families as well as for the professionals who shall treat these people. Francesca's important role will be used as a good example for the other projects in the developing programme of IF.

IF's 30th Anniversary

Knowledge Network

Improving the capacity of the IF network with the support of the European Commission

In 2008, the European Commission acknowledged the status of IF as a representative network of people with Spina Bifida and Hydrocephalus. It rewarded IF with a grant to carry out certain activities to improve the capacity of the network, to raise awareness about the conditions, to voice the concerns and expectations of people with Spina Bifida and Hydrocephalus and to reinforce the members' skills to do so at national level.

The mission of IF and its members is the same: primary prevention and improving quality of life of the children and adults facing these conditions. By bringing together all involved, IF is the network of knowledge on Spina Bifida and Hydrocephalus. This includes organisations, devoted experts, individuals with Spina Bifida and Hydrocephalus, their relatives and carers.

Parent organisations have proven to be a driving force in improving the situation of their children with these congenital impairments. In several countries they have made their politicians invest in a better care system, better integration in society, etc. However, due to prenatal diagnosis and falling birth rates, our

much needed organisations tend to become weaker. A second important change is that the target group is ageing, and new problems arise.
Furthermore, in less developed countries there is no tradition of organisations representing persons with a disability in the same way as in Western Europe.

IF and its members are mission-driven organisations OF (and not FOR) people with Spina Bifida and Hydrocephalus and their carers, nearly all run by volunteers. This approach is an asset, but the people involved do not invest enough resources in their own managerial and organisational capacity. All efforts are going to the direct needs of the target group. This is the case for IF, but even more so for its members.

IF, as a platform of exchange between its members, is modelling the increased investment in its own capacity and stimulates its members to do so in their own countries. Developing capacity will have an impact on the organisations' ability to achieve their mission.
By their nature, IF and its members are human rights advocates, raising awareness for prevention of the disabilities they represents, but also guarding the quality of care and the right to life of newborns and unborn children with these impairments. A free choice to terminate the pregnancy or not when the disability is detected prenatally is also depends on the availability of treatment and care. In some countries, very little care is available, or even none at all. Low economic resources should not be used as an excuse NOT to develop a good system of holistic care. IF, through its solidarity with people with Spina Bifida and Hydrocephalus in the South, has developed several good examples of good care with limited means. Less developed countries can learn from that experience, rather than from the industrialized world.

Spina Bifida and Hydrocephalus organisations worldwide are voicing the need for primary prevention actions. They make the problem visible. IF has developed an advocacy toolkit for its members, updated regularly and available online. The incidence of Spina Bifida can be reduced by pre-conception care and counselling and by food fortification with Folic Acid. Therefore, IF promotes the theme "Prevention" and raises the importance of the network and its visibility to the benefit of the general public. All women of childbearing age should know of Spina Bifida and the measures to prevent it. IF is working hard to get this message heard by international organisations and institutions, such as Unicef, WHO and the European Commission.

IF is planning a series of workshops and contributions to local meetings in order to address the needs of the members on organisations capacity and management. The well organised care of interdisciplinary Spina Bifida and Hydrocephalus teams all over Europe has to be transferred to the new member states. National member organisations are crucial to create awareness in this matter. IF wants to extend its network in Europe to all new member states, candidate member states or neighbouring countries.

IF's 35th member association

Asociatia Romana Spina Bifida si Hidrocefalie (ARSBH)

By Adriana Tontsch, President ARSBH

Every year approximately 600 children are born in Romania suffering with Spina Bifida and/or Hydrocephalus. That is 3 out of 1000 births. More than half of the children require urgent surgery for implantation of a shunt.

Romania has no national system for social and medical information. This results in a large number of children being discarded. Every year about 9000 children are abandoned and about 4000 are reintegrated in their families. The main reason is lack of information, poverty, sickness, and, among others, conditions such as Spina Bifida and Hydrocephalus. The Romanian Ministry of Health does not have the financial means to buy the necessary medical supplies. The consequence thereof is that too much time passes between diagnosis and treatment, which leads to irreversible (mental) disability.
In Romania there are no institutions which are suitable for the postoperative treatment, medical follow-up and rehabilitation of children with Spina Bifida and/or Hydrocephalus.

The Romanian Association of Spina Bifida and Hydrocephalus (ARSBH) complements the activities of the Ministry of Health by purchasing the shunts systems which are donated to the children suffering with Spina Bifida and Hydrocephalus.

ARSBH is a non-profit organisation established in 2005. Its mission is to improve the health status of the children suffering from Spina Bifida and Hydrocephalus. ARSBH has 38 contributing members, of which 20 are neurosurgeons.
The ARSBH activities are financed through donations and sponsorships collected with the help of non-profit organisations from Germany, "Hilfe für Wasserkopf Kinder in Rumänien" (HWKR) and from Austria "Mildtätiger Verein zur Unterstützung für Menschen mit Spina Bifida und Hydrocephalie". From the year 2008, Romania is, through ARSBH, a member of the International Federation for Spina Bifida and Hydrocephalus (IF).
The aim of ARSBH is to achieve medical treatment of children suffering with Spina Bifida and/or Hydrocephalus in Romania (implantation of shunts, post operative treatment and rehabilitation) so that the larger part of those children can be fully integrated into the community. We are very well aware of the fact that any postponement of the treatment can end in death or will bring about irreversible impairment for the child. ARSBH has donated shunts systems and many others medical supplies necessary to perform more than 450 surgeries.
Only in 2008, surgical operations have been carried out on more than 167 children with Spina Bifida and Hydrocephalus with the financial support of ARSBH. To make this possible, ARSBH purchased 74 shunts systems in value well over 100.000 €.

ARSBH is coordinating several other activities targeted to inform and instruct the families having children that underwent surgeries related to Spina Bifida and Hydrocephalus. Several other activities are directed towards instructing the medical professionals, reintegration into the family of the abandoned children and last but not least the social reintegration of children who have received treatment.
ARSBH financed and organized, in cooperation with Dr Manfred Schwarz from the University "Johannes Gutemberg" Neurosurgery Clinic from Mainz in Germany, a medical training for six Romanian neurosurgeons. The training focused on surgical procedures addressing Spina Bifida.

One of the highest priorities of ARSBH is the creation of the "National Centre for Treatment and Recovery of Children with Spina Bifida and Hydrocephalus". ARSBH already owns the land necessary for the construction. The architectural project is also finished and available. For the moment, ARSBH doesn't possess the necessary funds for the construction. Once built, this institution could become a model regional reference center for Spina Bifida.

Jan Jarab, EU Commission Vladimir Spidla, Adriana Tontsch, Lieven Bauwens after discussing the situation of people with Spina Bifida and Hydrocephalus in Eastern Europe.

Growing up ready – towards adulthood

After attending a Canadian-Swedish exchange programme IF board member Renée Höglin advocated for early planning of transition from childhood to adulthood at the 2007 IF Conference in Kampala. Director of Bloorview's Life Skills and Wellness Institute Helen Healy reported more extensively on the Canadian "Growing up ready" programme during IF's 2008 conference in Lisbon. Helen also became involved in the IF projects and participated in the 2008 IF African Workshop on Parental Hope in Arusha, Tanzania, where she presented a workshop on Growing Up Ready. The Canadian context questioned the potential cultural differences, but found that the material worked very well with minimal adaptation. As a result, IF continues to explore their interest in further work with youth with disabilities with the goal of self determination towards integration into community and school.
IF invited Helen to return to Africa to present a workshop in 2009 in Kenya which will include youth from 5 neighbouring countries.

Growing Up Ready is a multidisciplinary programme that promotes the acquisition of life skills among children with disabilities such as Spina Bifida and Hydrocephalus from an early age, preparing them stage by stage, as developmentally appropriate, for transition to the most active and independent adulthood possible.

One of the most significant outcomes of Growing Up Ready is the development of the LIFEspan service for the transition of youth with disabilities from paediatric to adult health care. To develop this concept and its services, Bloorview cooperated closely with adults with Spina Bifida and parents of children with this condition. Parents and Youth were employed as colleagues in their staff. This cooperation between professionals and persons with the condition was key for the success of the Growing Up Ready programme.

International interest in the Growing Up Ready model is unprecedented. The model is being recognized around the world as a leading practice.

With better medical care, children with disabilities are living longer and becoming adults. They have to leave their parents' home – but are they ready for the future? Have they learned the skills they need to live on their own? They expect to live productive, meaningful lives. They need to be ready to participate in life. Bringing up a child with a disability usually means that they are not expected to do what other children their age do. Parenting a child with a disability does not come naturally.

Children need encouragement to be the best they can be. They need encouragement in their family, in their community, at school and later on as adults. Although children's abilities will vary, they should not be underestimated. Parents should have expectations for their child and encourage their child to expect the best from themselves. What they can do by themselves, they should do by themselves. Children should be given the chance to learn and develop skills, both in their community and at school. They also need to learn about their disability and their health care needs. Parents need to start early to help their child grow up and reach the highest level possible of independence.

Health care professionals can contribute to the transition of the child into adulthood as well. They can increase their efforts to help the child by thinking about the future, fostering independence and problem solving, looking for chances to practice and master skills and by planning for changes and celebrating them.

The most important factor for a successful transition from childhood into adulthood is the child itself. This starts with the child not seeing itself as being disabled. With the support of friends and family children with a disability should be encouraged to live life as any other child would. This includes doing household chores, having friends, going to school, learning to care for themselves, engaging in hobbies, sports and learning to think and speak up for themselves.
Promoting independence and life skills are key issues in the Bloorview's Growing Up Ready programme, as well as the close cooperation between youth, family and health care professionals.

Resources
Growing Up Ready material can be downloaded from the Bloorview web site, www.bloorview.ca.
Helen Healy & Associates at **helenhealy@live.com** for teaching and program development.

Members of the International Federation for Spina Bifida and Hydrocephalus

Algeria
Association des malades de
Spina Bifida de Mostagenem
villa no83 chemins de crètes
(Mazagran)
Mostagenem 27120
www.spinabifida27.unblog.fr

Argentina
Asociación para Espina Bifida e
Hidrocefalia (APEBI)
Fragata Presidente Sarmiento
829/831
C1405AXB Ciudad Autónoma
de Buenos Aires
www.apebi.org.ar

Australia
Australian Spina Bifida & Hydrocephalus Association (ASBHA)
Spina Bifida Association of WA,
The Niche, Suite B 11 Aberdare
Road
Nedlands 6009
www.asbha.org.au

Austria
Spina Bifida und Hydrocephalus
Österreich (SB&HÖ)
Postfach 88
1234 Wien
www.sbho.at

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

Brazil
Associação de Espinha Bifida e
Hidrocefalia do Rio de Janeiro
(AEBH) Av. Prefeito Dulcídio
Cardoso, 2500 - Bloco 1 - Apto
606 - Barra da Tijuca
22631 -051 Rio de Janeiro – RJ
www.aebh.org

Canada
Spina Bifida and Hydrocephalus
Association of Canada (SBHAC)
/ Association de spina-bifida
et d'hydrocéphalie du Canada
(ASBHC)
428-167 Lombard Avenue
Winnipeg MB R3B OV3
info@sbhac.ca
www.sbhac.ca

Denmark
Rygmarvsbrokforeningen af
1988
Egebaeksvej 28
8270 Højbjerg
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

France
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spinabifida.france@wanadoo.fr

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Arbeitsgemeinschaft Spina
Bifida und Hydrocephalus e.V.
Bundesverband (ASBH)
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44145 Dortmund
www.asbh.de

Guatemala
Asociación Guatemalteca de
Espina Bífida (AGEB)
7a ave. A 4-31 zona 9
Ciudad de Guatemala
ebguatemala.blogia.com/

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

Italy
Federazione Associazioni Italiane Spina Bifida e Idrocefalo
(FAISBI)
Via Duomo n 20
29020 Settima di Gossolengo (PC)
www.faisbi.it

A.S.B.I. Associazione Spina Bifida
Italia
Via Duomo n 20
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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, 7763 Bissen
www.spina-bifida.lu

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Hydrocephalus
Postbus 3359
3502 GJ Utrecht
www.bosk.nl

Norway
Ryggmargsbrokk- og hydrocephalusforeningen
Brynsveien 96,
1352 Kolsaas
www.ryggmargsbrokk.org

Peru
Asociacion Peruana de Espina Bifida e Hidrocephalia Arequipa (APEBHI)
Av. La Capilla 1151
Cerado Arequipa

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

Poland
Stowarzyszenie Chorych z Przepukliną Oponowo-Rdzeniową R.P. (ASBP)
ul. Organowa 2/73
20-882 Lublin
www.spinabifida.w.interia.pl

Portugal
Associação de Spina Bífida e Hidrocefalia de Portugal (ASBIHP)
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asbihp.blogspot.com

Romania
Asociatia Romana de Spina Bifida si Hidrocefalie
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Sector 4, Bucuresti
www.arsbh.ro

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

Scotland
Scottish Spina Bifida Association (SSBA)
The Dan Young Building; 6
Carighalbert Way
Cumbernauld G68 0LS
www.ssba.org.uk

Slovakia
Slovenská spoločnosť pre
Spina Bifida a/ alebo Hydrocefalus, o. z.
SNP 14
91904 Smolenice
www.sbah.sk

Spain
Federación Española de Asociaciones de Espina Bífida e Hidrocefalia (FEBHI)
Calle Pechuan nº 14, local bajo
28002 Madrid
www.febhi.org

Associació Catalana d'Espina Bífida i Hidrocefalia (ACAEBH)
C/ Sorolla 10
08035 Barcelona

Sweden
Riksförbundet för Rörelsehindrade Barn och Ungdomar (RBU)
Box 8026, S:t Eriksgatan 44, 3 tr
104 20 Stockholm
www.rbu.se

Switzerland
Schweizerische Vereinigung zugunsten von Personen mit Spina Bifida und Hydrocephalus (SBH)
Geschaftsstelle SHB CH,
Schulrain 3,
6276 Hohenrain
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)
ASBAH House, 42 Park Road
Peterborough PE1 2 UQ
www.asbah.org

USA
Spina Bifida Association of America (SBAA)
4590 MacArthur Blvd.,
NW Suite 250
Washington, DC 20007
www.sbaa.org

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Financial result in 2008

Statement of the auditor

REPORT OF THE AUDITOR ON THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31-12-2008 ADDRESSED TO THE GENERAL MEETING OF "INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS"
(Cellebroersstraat 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 31-12-2008, prepared under the responsibility of the board of directors of the federation, which show a balance sheet total of € 370.345,12 and a loss for the year of € 545,38.

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 31/12/2008 give a true and fair view of the federation's 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 26th 2009

BVBA De Nul & co
Auditor

Signed and represented by
Roger De Nul

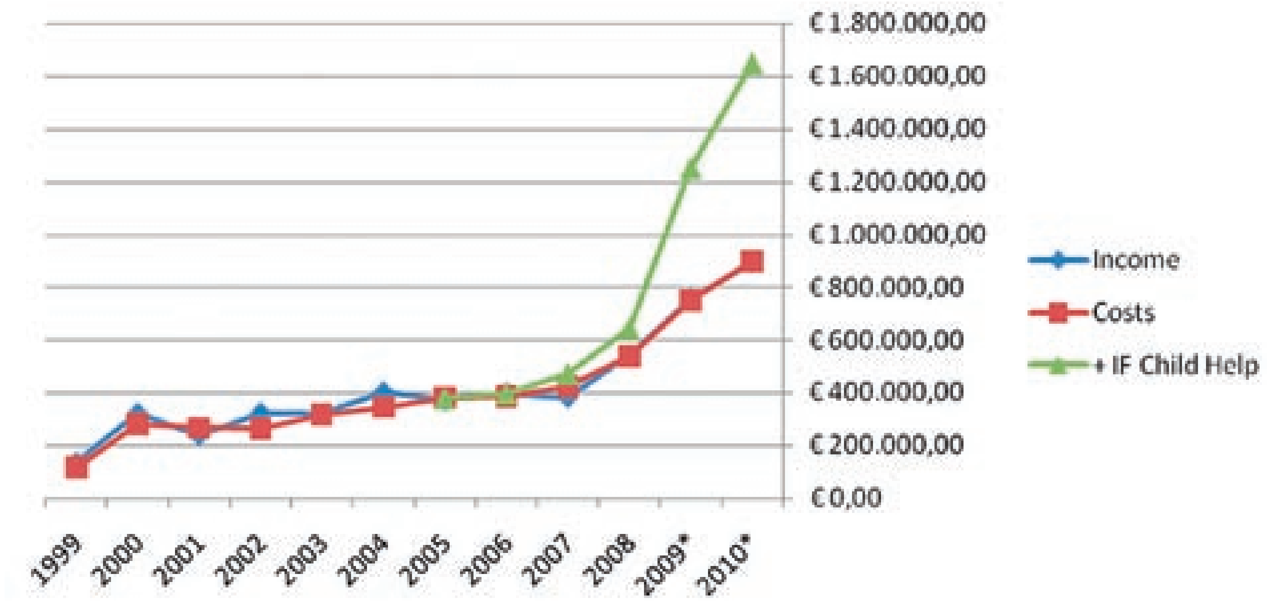
Balance sheet at 31 December 2008

Assets	**31-dec-08**	**31-dec-07**	**Liabilities**	**31-dec-08**	**31-dec-07**
TANGIBLE ASSETS	3.223,48 €	2.347,64 €	RESERVES	294.063,02 €	294.608,40 €
Investments	16.087,07 €	12.547,80 €	Funds of IF	294.608,40 €	336.085,13 €
Depreciations investments	-13.394,38 €	-10.730,95 €	Profit-losses reported	0,00 €	0,00 €
Cautions	530,79 €	530,79 €	Profit-los bookyear	-545,38 €	-41.476,73 €
AMOUNTS RECEIVABLE	83.271,18 €	42.776,59 €	AMOUNTS PAYABLE	76.282,10 €	23.649,13 €
Custumors	36.892,02 €	10.045,06 €	Suppliers	40.055,17 €	9.046,37 €
Subsidies to receive	25.000,00 €	0,00 €	Provision holiday fee	7.814,83 €	11.342,94 €
Projects current accounts	0,00 €	800,00 €	Projects current accounts	28.412,10 €	3.259,82 €
Divers to receive	418,20 €	1.933,16 €			
IF Child Help current account	20.960,96 €	29.998,37 €			
BANK & CASH ACCOUNTS	268.744,29 €	270.032,34 €			
Stocks	19.892,20 €	198.750,25 €			
KBC - accounts	21.085,58 €	12.832,52 €			
KBC - accounts saving	227.645,57 €	57.869,16 €			
Pay pal	120,94 €	580,41 €			
TRANSIT ACCOUNTS	15.106,17 €	3.100,96 €	TRANSIT ACCOUNTS	0,00 €	0,00 €
Costs for next year	15.106,17 €	3.100,96 €	Profits for next year	0,00 €	0,00 €
Total assets	**370.345,12 €**	**318.257,53 €**	**Total liabilities**	**370.345,12 €**	**318.257,53 €**

Profit and Loss 2008

	OUT	IN	
Diverse costs	**402.201,32 €**	**533.295,85 €**	**General income**
Rent	7.632,75 €	7.040,00 €	Membership fees
Office cleaning	167,60 €	2.610,00 €	Donations - fundraising
Energy	2.175,76 €	25.000,00 €	Other grants
Office supplies	3.911,19 €	212.963,73 €	Subsidies project Norad
Publications - copy	14.562,75 €	37.514,83 €	Subsidies project SHIA
Documentation - books	558,43 €	125.000,00 €	Subsidies project EU-project
Formation - education	438,34 €	843,48 €	Recuperation salary costs
Website	4.130,51 €	122.323,81 €	Diverse recuperation
Telephone - fax - mail	3.102,79 €		
Postal costs	645,83 €	**7.434,25 €**	**Financial income**
Transporters	2.062,30 €	5.107,58 €	Financial products
Membership fees	595,00 €	2.326,67 €	Payment + change difference
Fee translater	248,05 €	2.251,14 €	Change differences
Fee bookkeeper	3.152,74 €		
Fee auditor	1.482,25 €	**144,37 €**	**Exceptional income**
Fee social secretary	2.484,37 €	144,37 €	Exceptional income
Fee medical secretary	160,64 €		
Other fees	8.163,69 €		
Insurance	679,09 €		
Transport expenses	36.917,50 €		
Official documents (visas)	620,93 €		
Representation	30.517,24 €		
Medical material projects	126.899,96 €		
Salary's in projects	50.302,17 €		
Training projects	30.523,42 €		
Other expenses projects	50.497,72 €		
Conferences - meetings	19.568,30 €		
Salary	**127.824,62 €**		
Gross salary	96.504,24 €		
Social charges	23.237,68 €		
Insurance	2.574,70 €		
Personnel IF abroad	5.508,00 €		
Depreciations	**2.663,43 €**		
Depreciations	2.663,43 €		
Financial costs	**8.730,48 €**		
Bank charges	1.693,68 €		
Loss on stocks	6.689,22 €		
Payment & change differences	347,58 €		
Total costs	**541.419,85 €**	**540.874,47 €**	**Income**
	Result :	**-545,38 €**	

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

Intertnational Partnerships

Other International NGO's

Companies

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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 and EU candidate and pre-candidate countries.

To that effect, PROGRESS purports at:

- providing analysis and policy advice on employment, social solidarity and gender equality policy areas;
- monitoring and reporting on the implementation of EU legislation and policies in employment, social solidarity and gender equality policy areas;
- promoting policy transfer, learning and support among Member States on EU objectives and priorities;
- and relaying the views of the stakeholders and society at large.

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

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INTERNATIONAL
FEDERATION
for
SPINA **B**IFIDA
and
HYDROCEPHALUS

IF ivzw

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

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