

Annual Report 2009



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

Annual Report 2009

Presented on the General Meeting of the International
Federation for Spina Bifida and Hydrocephalus
10 June 2010
City West Golf & Leisure Resort, Dublin, Ireland

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Introduction

The Barack Obamas of the IF network

It is probably the location, Walt Disney World in Orlando, Florida, that inspired our American member association SBA to propose the theme 'Imagine the possibilities' for our successful 2009 IF conference.

Imagine the possibilities of an ordinary grey little mouse before he acquired a new shape and the funny name Mickey from his creator Walt Disney.

Mickey Mouse eventually became an icon like Barack Obama already was, in a way, when running for president. Icons are like role models and they inspire our imagination.

Role models within our network show that Spina Bifida and Hydrocephalus should not hinder our dreams. Quite the opposite is true. Limitations make us more aware of our possibilities. Creative processes build on imagination. Imagination is the start of something new. It creates hope.

Hope creates action in adults with Spina Bifida and Hydrocephalus planning family life and a career; in parents investing in the future of their children; in professionals giving part of their lives to our mission.

IF builds on all these wonderful people. We are blessed with many role models within the network. Let me present to you just some of them.

In 2009 two young women with Spina Bifida within our close network gave birth to a son. Olga De Wit, a Dutch medical doctor, became the proud mother of Daniel and Vicky Sandoval, a Guatemalan lawyer, of Martin.

IF's vice-president Eli Skattebu became a role model for generations of Norwegian and African children with Spina Bifida and Hydrocephalus due to her work in our Norwegian association and the work of solidarity in Africa.

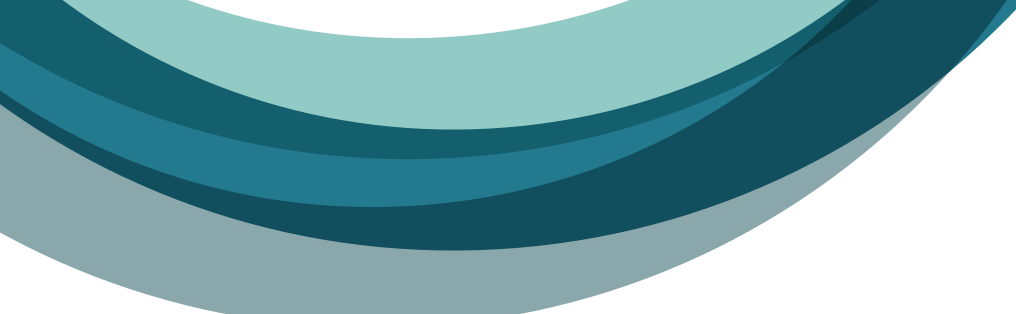
Dr. Bransford called his firstborn child Bethany and imagined that this healthy baby could give him the power to give a new direction to his life. He and his wife Millie adopted a Kenyan boy with Hydrocephalus and as an American surgeon, he created the Bethany Kids Hospital that now takes care of hundreds of children with Spina Bifida and Hydrocephalus annually.

That is the reason he received the IF Award 2009.

At the 5th anniversary of Bethany Kids Caroline Wanjira, a role model from Kenya who represents her country in the national wheelchair basketball team, thanked IF and Bethany Kids for her life with the words: 'I am beautiful, I know it, and am proud of it'.

Bo Hjelt, a businessman and previous member of the IF board, recipient of the 2006 IF Award, father of 3 children with Spina Bifida, who created his Bo Hjelt Foundation to finance fundamental research into the causes of Spina Bifida.





James Wilkinson, a Minnesota public interest lawyer, was travelling with his wife in Paris when she had a stroke. The event changed both their lives dramatically because of the impairments remaining after rehabilitation. In 2009 he took a sabbatical and part of his leave he offered to IF as legal adviser to study the rights of newborns regarding access to available treatment.

All these persons transformed adversity into challenges, to achieve goals that are of benefit to others.

I am amazed by the actions and creativity within the IF network.

All IF's work is driven by many more people than I can mention in this introduction. But due to their dedication to help others, the IF network of knowledge became a place of hope and 'the place to be' to learn more about new opportunities worldwide. Because of these role models the IF network has gained increasing international recognition as a human rights advocate for availability and accessibility of care for all. They are voicing the concerns of persons with Spina Bifida and Hydrocephalus, also in developing countries.

The 2009 African IF workshop in Kenya on inclusive education had the Swahili theme 'Hodi' or 'Can I come in?' The successful workshop showed how African parent groups really make a difference imagining their possibilities towards an inclusive society. Parallel, East African adults with Spina Bifida and Hydrocephalus had their own workshop summarising their work in a wonderful song at the end of the event.

Fortunately the worldwide financial crisis did not hamper our dreams. Due to our actions and projects we achieved a financial growth of 15% in 2009. Including all development cooperation projects, we can even talk about a growth of more than 100%.

Our work on primary prevention was rewarded with a Millennium grant of the Dutch government to train African millers and government officials on fortification of staple foods.

Role models within our network inspire us to reach these excellent results. Even if not everybody can achieve what others do, these Barack Obamas in the IF network let us imagine the possibilities.

I thank all who make these dreams happen. My board, the members of the African working group, the IF staff, FFI and all experts, the cooperating NGO's and agencies, and also you for your continuing commitment to provide a better life for our target group.

I wish that this annual report might inspire your imagination in your future work and cooperation with us.

Pierre Mertens
President IF

2009

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 2009:

IF as an organisation

- IF Child Help continues fundraising campaigns in Belgium
- Renewal of IF's participatory status
- New staff member Development Cooperation
- Grant Millennium Fund The Netherlands

Prevention

- Close cooperation with FFI
- Preparation NTD report "Act against Europe's most common birth defects"
- Smarter Futures project

Human Rights

- Partnering with the European institutions (EU, EC, EP, EDF) as NGO representing people with Spina Bifida and Hydrocephalus
- Preparation publication Healthcare Eastern Europe
- Publication Position Paper Groningen Protocol

Development Cooperation

- Over 4,800 surgeries, over 15,000 children in follow-up
- 1 neurosurgeon trained in the iPATH programme
- 1 nurse trained for the IF Projects
- IF African Workshop 2009 "Hodi" on Inclusive Education
- Training for Trainers, Dakar, Senegal
- IF Award Dr. Richard Bransford
- Photo exhibition IF projects Ugandan parliament
- Photo exhibition "[dis]ability", living with a disability in Uganda

Knowledge Network

- Three new members (Mexico, Colombia, Serbia)
- Successful annual conference in the USA
- Development of volunteer network
- IF EU Workshop Ireland
- IF Workshop Prague

Financial Stability

- Achieving EU funding for 2009 onwards
- Tax deductibility IF Child Help
- Continuing private donor support
- Ongoing financial commitment from Norway and Sweden



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 and Mrs. Maria Cristina Dieci

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. Luís Quaresma, Portugal
Mrs. Thelma Cloak, Ireland
Mrs. Maria Cristina Dieci, Italy

The board met in person in June and December 2009.

Staff

Brussels office:

Mr. Lieven Bauwens, Secretary General
Mrs. Els De Clercq, Coordinator Development Cooperation
Mrs. Katalijne Van Diest, Coordinator Development Cooperation
Mrs. Renée Jopp, Communications officer

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 (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 counseling
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



Prevention

Folic Acid NewsUpdate

IF is a strong advocate for prevention of neural tube defects through primary prevention. Primary prevention involves nutrition (Folic Acid fortification or supplementation) and preconception care.

IF organises and takes part in campaigns to raise awareness and supports its members in lobbying activities with their governments. IF creates and distributes the European Folic Acid NewsUpdate every three months.

FFI Workshop Skopje, Macedonia

In 2009 IF participated in the UNICEF Workshop on flour fortification in Skopje, Macedonia. Participants were urged to work with industry and host governments to ensure flour consumed in their countries was fortified with micronutrients. Fortifying flour is a proven cost effective strategy to improve population health and productivity. Representatives from milling industries, milling associations, bakers' associations, public health officials, food standards and food safety experts from eight countries in the region participated in the workshop. While the workshop was organised to provide the technical knowledge on how to implement flour fortification, participants also gained technical knowledge on how to conduct a cost benefit analysis and how to develop a flour fortification strategy and action plan.



FFI's executive officer Mrs Hye Kim, FFI's liaison Mr Robert Baldwin and the Health Minister of Macedonia Mr Bujar Osmani

Smarter Futures

Together with the Flour Fortification Initiative (FFI), AkzoNobel, BOSK and with support from the Dutch Ministry of Foreign Affairs, IF is involved in a 3-year project in Africa, called "Smarter Futures". The participants of this project are working together to make flour fortification standard milling practice in Africa. In December 2009 IF was involved in a Training for Trainers in Dakar, Senegal, together with partners such as FFI, Unicef, GAIN, CDC and Helen Keller International. Representatives of 17 West African countries took part in the training. Millers, public health and regulatory staff discussed the various technical aspects of fortification and harmonization of procedures, visited the Grands Moulins of Dakar and developed a training workplan for their country. These new trainers will now train other key personnel and stakeholders in order to ensure that the national fortification programmes can be implemented correctly.

NTD report Act against Europe's most common birth defects

At the time of writing this annual report, 59 countries worldwide have introduced mandatory flour fortification, yet none of the countries in Europe have installed this measure. Throughout 2009 IF has been cooperating with Bayer Healthcare to help prepare a report with an inventory about the prevalence of Neural Tube Defects (NTDs) in a number of European countries and national measures that have been implemented to prevent them. The report will be used to raise awareness about NTDs and the importance of primary prevention.



Mandatory fortification of bread in New Zealand

IF also responded to the consultation of the New Zealand Food Safety Authority in a bid to prevent the deferral of mandatory fortification of bread with Folic Acid. In spite of the proven benefits, the New Zealand government decided to delay commencement of mandatory fortification until 31 May 2012. Bakers in New Zealand will start with voluntary fortification of bread. Downside of this measure is that not all women of child-bearing age will be reached.

The Bo Hjelt Spina Bifida Foundation

The father of a child with Spina Bifida who passed away at the age of 11 and two unborn children also affected by Spina Bifida, Bo Hjelt set up the Bo Hjelt Foundation with the aim to help finance research in prevention of Spina Bifida in 1986.



Every year since then and until 2005, a percentage of the profits made by the company he founded and built (CDI) went into building a capital base for the Bo Hjelt Foundation. In recent years, Bo Hjelt has personally dedicated a significant sum of money and time to expanding the foundation's resources and capital/reach.

He has been a board member of IF for 8 years, actively involved in several fundraising events for the organisation, and in 2006 he received the IF Award for his dedication towards fulfilling IF's mission and goals.

From 1986 the Bo Hjelt Foundation sponsored the research on Spina Bifida of Professor Tom Eskes, Professor Emeritus, Department of Obstetrics and Gynaecology at University of Nijmegen in The Netherlands. From the beginning of the 21st century research projects of the research line of Professor Regine Steegers-Theunissen, Department of Obstetrics and Gynaecology, Epidemiology, Paediatrics and Clinical Genetics, Erasmus University Medical Center, have been financially supported.

The findings of this research support the recommendations of Folic Acid use of women of childbearing age, but stress the importance to find the lowest and safest dose. It also shows that not a single cause can explain Spina Bifida but that many factors, playing in concert, are involved. These factors vary from nutrients, medication, and lifestyles, such as smoking, to small genetic variations. This research also stimulated preconception care developments as well as the implementation of the research results into the first clinic on "healthy pregnancy" with a focus on nutrition and lifestyle at the Erasmus MC, in Rotterdam, The Netherlands.

Over the years, the Bo Hjelt Foundation has contributed in the financing of 10-15 PhD students active in fundamental research in the field of Spina Bifida. They in turn have produced some hundred articles in high-ranking medical journals.

Progress has been dramatic in the last 20 years, yet Spina Bifida is still one of the most common congenital birth defects, affecting between one and two out of every 1000 newborns. Therefore the Bo Hjelt Foundation continues to finance research in various areas of prevention.

1. Preventing more cases of Spina Bifida

Great strides have been made with the discovery of the protective effect of Folic Acid, yet not all Spina Bifida is responsive to this B vitamin. Therefore research needs to continue. Underlying mechanism and treatments are urgently needed to be identified to further prevent Spina Bifida.

2. Improving preconception counselling for Spina Bifida

Experts think that genetic factors in combination with environmental factors are important in Spina Bifida, but the critical genes and epigenetic modifications by environmental (risk)factors have not yet been identified. The discovery of these genes and modifications would make it possible to develop preconception tests that would give parents more precise information about their risk of having a baby with Spina Bifida.

3. Improving prenatal diagnosis for Spina Bifida

Advances in ultrasound techniques and a better understanding of embryonic neural tube and brain development resulted in possibilities to diagnose Spina Bifida already at the end of the first trimester of pregnancy.

Further improving the techniques to diagnose Spina Bifida in the earliest stages of a pregnancy would open the possibility to study neural tube development in relation to embryonic growth against the background of (epi)genetic and environmental (risk) factors.

4. What goes wrong in the embryo leading to Spina Bifida?

Much research around the world is aimed at understanding how the neural tube closes and what goes wrong in Spina Bifida. It is a complex subject, and requires sophisticated studies of molecules and cells in the early embryo. If scientists can fully understand the processes of neural tube closure, they will be able to discover, for the first time, how Folic Acid works in preventing Spina Bifida, and how genes and environment interact to cause this defect.

The Bo Hjelt Foundation and IF are working close together to advance the research into Spina Bifida and are aiming to create a European network of researchers to achieve their goals.

The Board of the Bo Hjelt Foundation consists of Enno D. Wiersma (chairman), Andrew J. Copp, Bo Hjelt, Paola Hjelt, Bart van Leemput, Pierre Mertens, Alexander Smits van Oyen and Regine Steegers-Theunissen.

More information can be found at www.hjeltfoundations.org



Human Rights

Central and Eastern Europe

IF wants to improve conditions for children with Spina Bifida and Hydrocephalus in Central and Eastern Europe.

Throughout 2009 IF has been gathering information about the care and living conditions for children with Spina Bifida and Hydrocephalus in Romania, in close cooperation with its member organisation in Romania, ARSBH. Interviews have been held with children and/or their parents and with neurosurgeons, visits have been made to hospitals in Bucharest and Alba Iulia, and to an orphanage. All too often children are either not treated, or are abandoned by their parents and left in state institutions. Without the help of ARSBH, who provide shunts for the treatment of Hydrocephalus and information for parents, many children would suffer a horrible fate. Romania was chosen as an example, but the situation is similar in countries like Bulgaria and Serbia. The results of IF's research will be published in a special booklet, which will be presented in 2010.



Eduardo Fernandez-Zincke (Cabinet of Commissioner Vassiliou), Jan Jarab (formerly Cabinet of Commissioner Spidla – currently Regional Representative for Europe of the United Nations High Commissioner for Human Rights), Jana Biedermannová

In Brussels IF met with Jan Jarab, Eduardo Fernandez-Zincke and Jana Biedermannová, Cabinet Members of the European Commissioners Spidla and Vasilliou, to discuss issues concerning children with Spina Bifida and Hydrocephalus in Central and Eastern Europe. IF emphasized the importance of involving the parents and not just the specialists in future plans to change the situation. People should be made aware of the rights of children with Spina Bifida and/or Hydrocephalus. They have the right to live, they are part of society, and they are entitled to proper care. During the meeting, other topics of discussion were the treatment of Spina Bifida and Hydrocephalus and prevention of Spina Bifida through flour fortification with Folic Acid.

IF also met with Vilma Tyler, nutritionist at the Unicef Regional Office for Central and Eastern Europe and the Commonwealth of Independent States (CEE/CIS) in Geneva, Switzerland, to discuss opportunities to cooperate in Central and Eastern Europe to improve the situation of children with Spina Bifida and Hydrocephalus in the new member states and decrease the prevalence of these impairments.

Quality of life

In 2009 IF President Pierre Mertens gave lectures at several conferences to share IF's point of view on care and quality of life for people with Spina Bifida and Hydrocephalus. Among others he lectured in New York, USA, Verona, Trento, Torino and Ravenna, Italy, in Madrid, Spain and in New Delhi, India. IF emphasizes that all parties involved, care seeker, professional care giver, family members, volunteers, are experts in their own field and working together can improve the quality of care and the quality of life for people with a disability or chronic diseases.

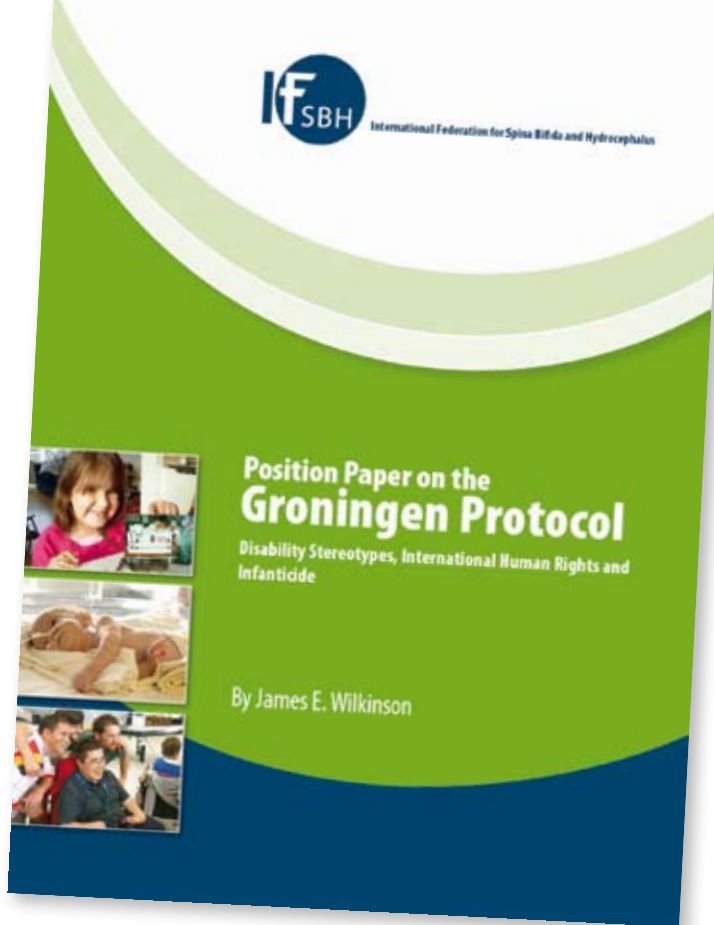
He also lectured about the right to live and the right to proper treatment. IF continues to stress the importance of looking beyond a disability and seeing an unborn child and a person with a birth defect or other chronic condition as a human being.

Position Paper Groningen Protocol

In the Netherlands it is possible to actively end the life of a newborn baby, if a doctor follows certain guidelines, proposed by a group of neonatologist, the so-called Groningen Protocol. The protocol describes the requirements for the termination of life of newborns with severe conditions who are diagnosed to be suffering "unbearably" and "hopelessly".

During the summer the IF staff was joined by Mr. James Wilkinson, who started working as a volunteer at the IF office in Brussels. He took a sabbatical from his work as a human rights lawyer at an NGO in the US, The Legal Aid Society. His work for IF focused on strengthening international human rights arguments against euthanasia of children born with severe disabilities. He received a fellowship from the University of Minnesota Human Rights Center to support his project at IF, which is done in support of the positions established by IF and its allies in the past decade.

In addition to meeting IF board and staff and with Spina Bifida Association participants at the International Conference in Orlando, Florida in July, Mr. Wilkinson has consulted with experts from the European Disability Forum, the European Commission and other sources. His extensive research resulted in IF's Position Paper "The Groningen Protocol - Disability Stereotypes, International Human Rights and Infanticide", which was distributed to all the members of the European Parliament.



The paper concludes:

International human rights instruments set the standards for legal and humane medical treatment recommendations for all people. Giving parents accurate multi-disciplinary information about the medical, social and life prospects of their newborn child in a non-directive and non-judgmental manner will cost little and go far to attaining those goals. Practices, like the Groningen Protocol, that counsel parents that it is best for babies to die because they have severe impairments violate international human rights standards. States adhering to those standards must overturn medical practices that counsel for the death of infants because of stereotyped negative judgments about the worthiness of life with a disability.

At the end of 2009 IF Board Member Teije Dijk participated in a debate in the Netherlands about the termination of life of those who are without the capacity to decide for themselves. Specialists in the Netherlands seem to have opposing views. Some are against the termination of life of newborns, others want to extend the rules of the Groningen Protocol. At the same time, a TNO report was released in the Netherlands which gives reason to suspect that prenatal diagnosis causes more and more parents-to-be to terminate a pregnancy when the foetus shows a birth defect. Both IF and its Dutch member organisation issued statements to the press, advocating for correct information about Spina Bifida and emphasizing the right to live of people with a disability.



SERVICE, LEARNING AND NEW PERSPECTIVES AT IF

The offices in the small brick building in Brussels had a familiar feel. I'd worked in similar spaces during my legal career with the Legal Aid Society of Minneapolis, an NGO in the U.S. The bargain-priced shared work-space and collaborative working relationships of the small staff had a comfortable feeling. The sense that I was participating with an important force that is bettering the lives of disadvantaged people reinforced my decision to volunteer as a Legal Advisor to IF in 2009 with the support of the University of Minnesota's Human Rights Fellowship program. The English fluency of staff, supporters and board members made both my comfort and productivity possible, since my Flemish/Dutch language skills are nil.

Across the street from the IF office is a café, La Fleur en Papier Doré (Het Goudblommeke in Papier), famous as a meeting place of the Belgian painter René Magritte and other Surrealist artists and writers. I carried to Brussels a scoffing attitude towards Magritte and his art, rooted, I suppose, in the clichéd pop art green apple posters hung in too many dorm rooms of my youth. But as I explored Magritte's confounding images and the poetry of his titles, my expectations were upended - his art shifted my mind so that I looked on from a new perspective that challenges established and comfortable truths and refuses to accept realistic boundaries.

Across the street from La Fleur en Papier Doré is the IF office where Pierre, Lieven, Els and their sisters and brothers around the world refuse to accept boundaries of what is practical. They insist that a small organisation, with a little money, can empower Kenyans and others to provide inexpensive and community-based treatment for children with Spina Bifida. IF also challenged my own settled, comfortable and liberal perspectives on end-of-life medical care, quality of life, abortion and related issues as I worked through a disability rights-based analysis of the Groningen Protocol where the lives of severely impaired infants often depend on physicians' stereotyped views of life with disabilities, in the certainty of their "Clairvoyance."

By James E. Wilkinson

Read about Jay Wilkinson's human rights research for IF at page 16.

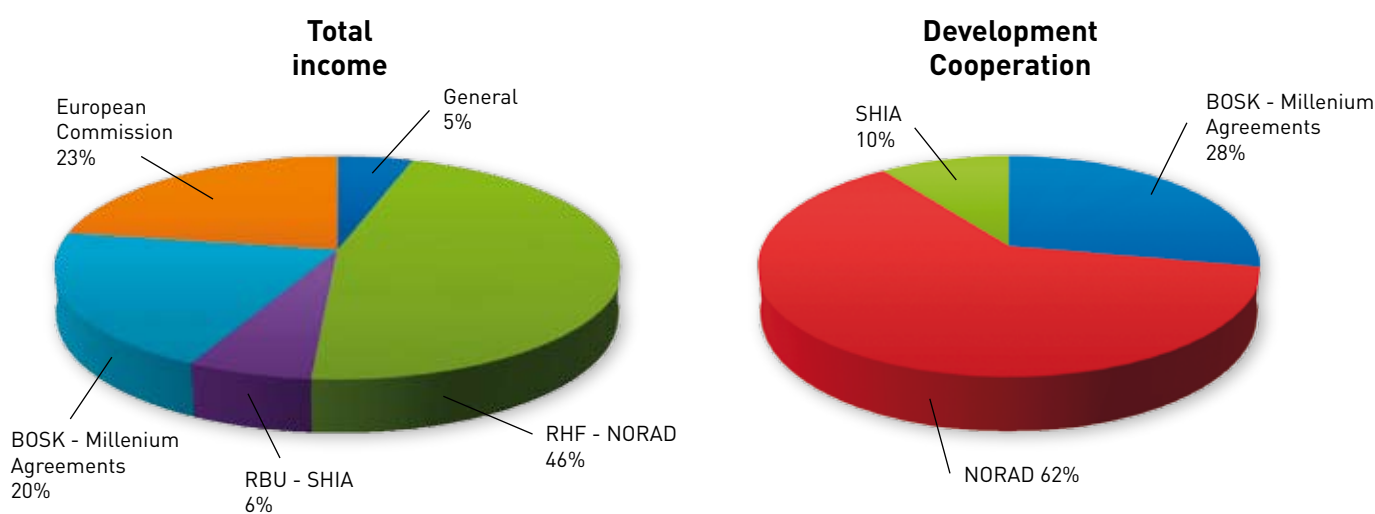
Development Cooperation

IF Projects in East Africa

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.

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)
- Mantana Grant
- Schokland Foundation (Millennium Agreements), the Netherlands
- IF Child Help



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

- Improve the basic local conditions for the treatment and rehabilitation of children with Spina Bifida and Hydrocephalus by organising appropriate training on all levels
- Empowerment of groups of parents and people with Spina Bifida and Hydrocephalus
- Social inclusion of people with Spina Bifida and Hydrocephalus and increase the expertise on rehabilitation and inclusion matters

- Increase knowledge on the diagnosis through research
- Assist and support NGOs to provide good services to people with Spina Bifida and Hydrocephalus
- Research on the causes and incidence of Spina Bifida and Hydrocephalus
- Primary prevention



The official partners in the countries where IF works are:

- Uganda, Mbale: CURE Children's Hospital
- Uganda, Kampala: Katalemwa 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)
- 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

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

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

Africa

Ivory Coast | Zimbabwe | Nigeria | Benin | Ghana | DC Congo | Ethiopia

Latin America

Peru | Bolivia | Honduras

Asia

Afghanistan | Bangladesh



Numbers and achievements in 2009

SURGERIES

- 2.600 shunts delivered to 23 partners in 20 countries.
- 1.184 shunt operations performed by the projects
- 517 ETV operations by CURE Hospital in Mbale, Kijabe, Beit CURE in Lusaka, Zambia and Bethany Kids in Kijabe, Kenya
- 537 SB operations performed by the projects

CHILDREN IN FU

- Total # children followed: 10.056 children with HC only; and 5.210 children with SB with/out HC
- 2.994 children are in CIC follow up
- 1.135 children are in bowel management follow up

TRAINING

- Annual workshop on Inclusive Education held in Nairobi, Kenya in October 2009: 42 African participants from 7 countries
- First Youth workshop held parallel to the annual workshop: 17 participants from 3 countries
- 27 training initiatives for professionals organised by the various projects
- 4.197 parents and their children attended a training on continence management

INCLUSION

- 205 children gone to school as a result of proper continence management
- Expanded network on Inclusive Education through the annual workshop
- Youth representatives are becoming more active in the support groups. Currently in 5 of our projects youth are already actively involved in the parent support groups by sitting in either the board or committees.
- More school directors and teachers are becoming involved in the projects. The annual workshop on Inclusive Education was attended by 8 school teachers and life skill trainers.

PARENT GROUP BUILDING

- 83 parent meetings organised by the projects, attended by more than 2.500 parents
- In all project countries parent groups have been established and are functioning. Now, more and more local parent groups are being set up in order to reach more parents in the rural areas. 6 new local groups were set up in 2009.

PREVENTION

- More than 668.000 Folic Acid tablets were distributed to over 3.500 women
- Early work in Uganda headed by Dr. Benjamin Warf has identified that neonatal infection is the main cause of Hydrocephalus. Research is now being planned to identify these pathogens and route of infection in order to reduce incidence through prevention.

First Youth workshop “HODI” By Eli Skattebu

From the start of our programme in developing countries the target group has been younger children and their families. Due to the enormous success of the programme, this first generation of young children has been able to survive; they are now young adults who have joined the group. Meeting these younger people has revealed a great need that is well known within the IF international network, but is even more important to be met where knowledge about the diagnosis is scarce. Younger people rarely know other people with a disability, and in their own surroundings there is much superstition about being different.

In the autumn of 2009 IF organised a workshop in Limuru, Kenya, the theme being inclusive education. For the first time a programme for younger people was listed. Being young and disabled is a great challenge, and the need for knowledge about one's diagnosis is very important. Why did I get this diagnosis and how does it affect my life? To know that the diagnosis is not caused by a curse or because someone in the family has done something wrong, is very important for a young person who is about to build his or her self-confidence and find his or her place in society and believe in one's capabilities.

With an open programme, all young participants could feel safe and ask questions. To receive the right kind of information together with other young people already created a positive atmosphere. Some participants had never met anyone with the same diagnosis and several very strong and impressive stories were told.

The participants discussed personal and sensitive questions, subjects they could discuss only with people in the same situation as themselves. Cognitive problems troubled a lot of youngsters and information about these particular problems became an 'aha'-experience.

In the end a bright 14-year-old boy stood with a pamphlet about cognitive problems in his hands and said: "I will give this pamphlet to my teacher. Then he will understand that I am not lazy or stupid, but that I struggle with cognitive problems". To get to know other people was exciting and strong friendships were built across different countries. The breaks and the evenings were efficiently used to exchange experiences and to enjoy music. At the end of the conference the group presented a song that was written by themselves,

“HODI KARIBU”:

Hodi Hodi Karibu
Will you let me in... 'cause I want to learn
I want to learn more about the world;
the world around me
Don't leave me out
I want to have a chance in Education

*Hodi = can I come in (Swahili language)
Karibu = welcome (Swahili language)*



The workshop showed how much strength and capacity there is in a group of youngsters. It is obvious for IF and all its partners that several young people should become more active in the parent groups. They have much to contribute and are able to reach out to more young people as well as to be a role model for others.

IF Award 2009 - Dr. Richard Bransford

The American surgeon Dr. Richard Bransford received the IF Award 2009 for his inspiring work at Bethany Kids at Kijabe Hospital in Kijabe near Nairobi, Kenya. At the plenary session of the SBA/IF conference in Orlando, Florida, attended by 750 participants, the award was presented to Dr. Bransford by Dr. G.D. Agrawal, founder-CEO of Surgiwear, long-term supplier of shunts and other medical material to the IF projects.

Dr. Bransford first visited Kijabe with his wife Milly in 1966, where he started working at Kijabe Hospital for three months. After finishing medical school and a general surgery residency, the Bransford family returned to Africa in 1972 and stayed there for another 5 months. They went to Congo in 1976 and moved to Kijabe once more in 1977. They have served there ever since.

In 1982 Dr. Bransford first became involved in the care of children with a disability. Although he had no expertise in this area, he managed to improve the care by learning from mistakes and through the involvement of more specialists. One of them was Dr. Scott Harrison. Together they started the Bethany Crippled Children's Centre in 1998, which became the first CURE Hospital, and the Kikuyu Rehabilitation Centre was completed at that time as well. Dr. Bransford worked at CURE Hospital until 2004.

Twelve years ago, Dr. Bransford and his wife Millie adopted a Kenyan child with Hydrocephalus that needed a shunt. He contacted IF to be able to help more children who needed a shunt. With the aid of the Norwegian association, Ryggmargsbrokk- og hydrocephalusforeningen, IF provided the Indian Chabbra shunt free of charge. This was the start of a programme for children with Spina Bifida and Hydrocephalus at the CURE Hospital.

In 2004, the enormous growth in the number of children with Spina Bifida requesting help at the CURE Hospital encouraged Dr. Bransford to look for expansion and he started a neuropaediatric division at the Kijabe Hospital. Now this division, Bethany Kids Kijabe, is performing around 2000 surgical interventions a year and it has become the reference centre for Spina Bifida and Hydrocephalus for all Kenya. With a network of outreach clinics, Dr. Bransford developed good postoperative care and started lifelong support for children with Spina Bifida.



SPINA BIFIDA AND HYDROCEPHALUS AT KIJABE

It all began rather innocently. A radio call came from northern Kenya, and I was simply asked if I would put in a shunt. There was a Rendille child with Hydrocephalus; inquiries in Nairobi about someone to put in a shunt bore no fruit. I asked my colleague, Dr. Bob Bowers, if he had ever put in a shunt. We concluded that neither of us had ever seen a shunt inserted.

That was in the early 1980's. Shortly thereafter, and I mean within a week, I received a letter from a Chinese neurosurgeon living in Los Angeles saying that he was going on a safari and wondered if he could have a tour of Kijabe Hospital. With much difficulty I called my brother in Los Angeles asking him to contact this person and tell him, "We would love to give you a tour. How would he like to put in a shunt?" He came. He put in a shunt. We gave him a tour. And, he left leaving behind one extra shunt.

During the next 15 years we put in the occasional shunt, possibly 5-6 a year, and we closed the back of occasional children with Spina Bifida. We had no further visits from a neurosurgeon for over 15 years. In 1997 we put in 7 shunts and closed the backs of 8 children.

The volume of patients coming began to grow in 2000 when we inserted about 35 shunts and closed the backs of a similar number of children with Spina Bifida. In 2009 we inserted 646 shunts and external ventricular drains and closed the backs of about 294 children with Spina Bifida. During the intervening years the help we received from committed nurses and an operating staff was invaluable. The 14 mobile clinics allowed us to provide a better degree of follow up for these patients. Parent groups were developed. Agnes Jeruto, our first neuronurse and the driving force for clean intermittent catheterization for Central Africa, taught her skills to innumerable parents as well as many nurses and lay people.

The network of need expanded and seems to continue to spread. In 1982 my work with the disabled began at the AIC Kajjado Child Care Centre. At that time most of the children had polio, burn contractures, club feet, cleft lips and similar problems. Only later did parents bring their children with Hydrocephalus and Spina Bifida. As the volume increased, we outgrew the resources of the Bethany Crippled Children's Centre and were asked to move the neurosurgical work back to Kijabe Hospital. BethanyKids at Kijabe Hospital was then born. The ensuing years also brought a burden for the children who had little or no access to care in other developing countries in Africa. Ethiopia, Tanzania, Madagascar, and most sub-Saharan countries either do not have the personnel to care for these children or do not have the resources to meet this need. Bethany Relief and Rehabilitation International and the International Federation of Spina Bifida and Hydrocephalus are often working together to find a means forward in providing care for these children. The task is immense.

When the work with the disabled began in 1982 there were no surgical specialists other than general surgeons. Now, at Kijabe Hospital, we have a plastic surgeon, a few orthopedists, two paediatric surgeons and three gynaecologists. Soon we will have a resident otorhinolaryngologist and paediatric neurosurgeon. The teaching program for doctors and nurses has grown wonderfully. In the midst of all of this more disabled children are receiving more care by more specialists, and a greater vision for expanding these services is evolving.

Dick Bransford



West African Training of Trainers in flour fortification

From 7-10 December 2009 seventy six representatives from the flour and baking industries of eleven West African countries and government officials from Health, Industry and Commerce Ministries of eighteen West African countries, as well as representatives from several international organisations such as GAIN, Helen Keller International, IF, UNICEF, FFI and the Micronutrient Initiative participated in a workshop organised by Smarter Futures in Dakar, Senegal to be trained as future trainers in flour fortification.

Smarter Futures is a three-year project which provides technical support and training for flour millers in Africa. Government food control staff are also included as they too are key partners in fortifying flour with vitamins and minerals. Fortification of flour with essential vitamins and minerals will improve people's health and well-being and lead to smarter futures.

The project also provides support for leadership training on the importance of nutrition in achieving improved public health and the Millennium Development Goals.

The partners involved are the Flour Fortification Initiative, AkzoNobel, Helen Keller International, the International Federation for Spina Bifida and Hydrocephalus (IF) and BOSK, with the financial support of the Ministry of Foreign Affairs of the Netherlands. They all work toward preventing problems caused by vitamin and mineral deficiencies, such as neural tube birth defects, impaired learning capacity and decreased productivity.

Flour fortification is one strategy for addressing such deficiencies because it delivers essential nutrients through staple foods and it does not require consumers to change their eating or buying habits.



The objectives of the Training for Trainers workshop were:

- to provide additional training on flour fortification (a multi-stakeholder activity) to key individuals at the country level;
- to provide the training tools for key individuals to be able to conduct training at country level for all stakeholders;
- to provide industry and government stakeholders with the same training programme.

During the workshop, the participants were given an overview of vitamin and mineral deficiencies and economic consequences, the current status of fortification at world and regional levels and discussed national flour fortification programmes, roles and responsibilities, regional standards development as well as monitoring and evaluation systems, including food quality and safety.

The workshop included a visit to the Grand Moulins of Dakar, the largest flour mill in the region, and the participants were given practical demonstrations of Quality Assessment and Quality Control tests and saw the production of flour as well as the fortification process in practice.

The workshop was evaluated as very useful and informative. The number of participants and countries represented exceeded all expectations. Participants were very positive about the workshop and stressed the importance of having both industry and government in the same workshop getting the same message. On return home, the participants will start training programmes at local level. In conclusion, the first Training of Trainers in flour fortification has been a huge success. A similar training is planned for East African countries in 2010.



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.



Expansion IF's membership

To reach as many people as possible IF is continuously looking for ways to expand its knowledge network. In 2009, during the General Meeting in Orlando, Florida, USA, three new members joined IF: Mexico, Colombia, and Serbia.

IF Annual Conference

Each year IF organises an international conference where all stakeholders can meet and receive and exchange information. In 2009 IF's 20th annual conference "Imagine the possibilities" was held jointly with the Spina Bifida Association (SBA) in America at the Swan and Dolphin Resort in Walt Disney World, Orlando, Florida, from June 30 until July 3. The conference was a great success and welcomed over 760 attendees from 46 states and 17 countries. A variety of topics was discussed during the educational sessions, from a Folic Acid update to latex allergy and bowel and bladder continence.

IF President Pierre Mertens was one of the speakers at the conference. IF's medical consultant paediatric neurosurgeon Ben Warf, received SBA's first place award for his work entitled Neurocognitive Outcomes for ETV/CPC (Comparison of Neurocognitive Outcomes and Ventricle Size in Myelomeningocele Infants Treated for Hydrocephalus by Shunting to Those Treated with Combined Endoscopic Third Ventriculostomy/Choroid Plexus Cauterization).

IF EU Workshop Ireland

With the support of the European Commission IF held a workshop on capacity building for its European member associations. The workshop took place in Ballinasloe, Ireland, prior to the annual conference of IF's Irish member SBHI. The participants represented 14 different countries. Aim of the workshop was to strengthen the network's capacity to advocate and voice the concerns of the target group. The workshop was facilitated by IF president Pierre Mertens and IF Secretary General Lieven Bauwens. Many participants gained relevant information and expected to be able to apply this knowledge in their associations. The IF president subsequently gave a lecture during the SBHI annual conference, confronting the audience with the negative stereotyping of Spina Bifida and Hydrocephalus, and explaining about the cost-effective and successful treatment of Hydrocephalus through ETV (Endoscopic Third Ventriculostomy).

IF Workshop Prague

IF is also working to extend its network into Central and Eastern Europe. In March 2009 a special workshop was organised for parents of children with Spina Bifida in Prague, Czech Republic, in conjunction with IF's Slovakian member organisation. Terezka Drdul spoke about the importance of a Spina Bifida organisation, how it can contribute to all aspects of life, and Dr. Frantisek Horn explained to the audience that "life is not only treatment".

Both Terezka Drdul and Dr. Frantisek Horn were part of a Slovakian delegation that visited the University Hospital in Leuven, Belgium, in January 2009 to meet with IF's medical advisors and volunteers, Dr. Carla Verpoorten and nurse Myleen Christiaens, to receive a short training about multidisciplinary care.

Development volunteer network

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

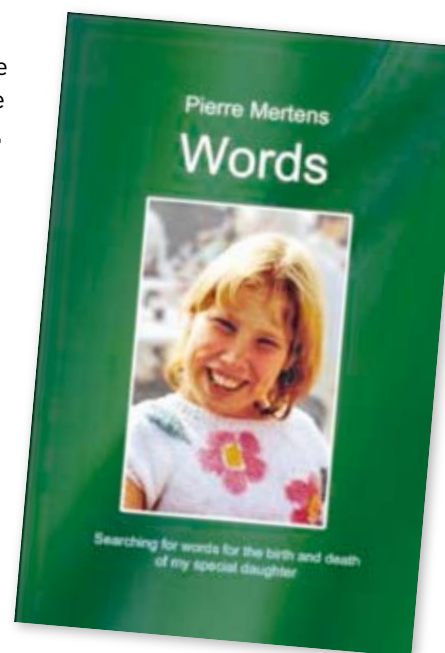
Also with the support of the European Commission, the IF website underwent a make-over in 2009. It is now easier for the IF staff to maintain the website and an effort was made to make the information more accessible. The text can be viewed in larger font sizes and each page can be converted to PDF format and can be printed. The IF website and IF newsletters are an important means for IF to share knowledge and reach as wide an audience as possible.

"Liesje"

In his book "Liesje", IF president Pierre Mertens searches for words for the life and death of his special daughter Liesje, who was born with Spina Bifida. While searching, words like disability, love, comfort, support, help, solidarity, health care, ethics, euthanasia and abortion took on a new meaning to him. The story of Liesje was first published in 2001 in the Dutch language. Next it became available in the French, Norwegian, Slovak and Italian language.

Now "Liesje" has been translated into English and has the title "Words". The book became available online in 2009 through the Blurb Bookstore, <http://www.blurb.com/bookstore/detail/739042>.

In Italy Pierre Mertens received a literary award this year for "Liesje, mia figlia". He also published a Dutch book called "Dad, what is a disability?", to change people's perception about what it is like to live with a disability.



Members of the International Federation for Spina Bifida and Hydrocephalus





Algeria

Association des malades de Spina Bifida
de Mostaganem
villa no. 83 Chemin de Crètes (Mazagran)
Mostaganem 27120
www.spinabifida27.unblog.fr

Argentina

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

Australia

Spina Bifida Association of WA
The Niche
Suite B11, Aberdare Road
Nedlands 6009
<http://www.sbawa.asn.au>

Austria

Spina Bifida und Hydrocephalus
Österreich (SB&HÖ)
Postfach 88
1234 Vienna
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 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

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

Colombia

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

Denmark

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

Estonia

The Estonian MMC and HC Society
Tervise 28
13419 Tallinn
www.kelluke.ee

Finland

Suomen CP-liitto ry
Malmin Kauppatie 26
00700 Helsinki
www.cp-liitto.fi

France

Fédération Française des Associations du
Spina Bifida (FFASB)
58 rue Pré Commun
31230 L'isle en Dodon
<mailto:spinabifida.france@wanadoo.fr>
www.spinabifida.fr

Germany

Arbeitsgemeinschaft Spina Bifida und
Hydrocephalus (ASBH)
Grafenhof 5
44137 Dortmund
www.asbh.de

Guatemala

Asociación Guatemalteca de Espina Bífida
(AGEB)
7 av. A 4-31 ZONA 9,
Ciudad de Guatemala
ebguatemala.blogia.com/

Ireland

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

Italy

Spina Bifida Italia
Via Duomo 20
29020 Settima di Gossolengo (PC)
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
<http://www006.upp.so-net.ne.jp/sbaj/>

Luxembourg

Association pour le Spina Bifida a.s.b.l.
5 Chemin de Bousberg
Boîte Postale 20
7703 Bissen
www.spina-bifida.lu/

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A.C. (AMEB)
Calle Maurice Baring # 295
Col. Jardines de la Patria
C.P. 45050
Zapopan, Jalisco
<http://www.facebook.com/group.php?gid=33253523321>

The Netherlands

BOSK Work Group Spina Bifida &
Hydrocephalus
Postbus 3359
3502 GJ Utrecht
www.bosk.nl

Norway

Ryggmargsbrokk- og hydrocephalus-
foreningen
Brynsveien 96
1352 Kolsås
www.ryggmargsbrokk.org

Peru

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

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

Poland

Stowarzyszenie Chorych z Przepuklina Oponowo-Rdezeniowa R.P. (ASBP)
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20-853 Lublin
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Portugal

Associação Spina Bifida e Hidrocefalia de Portugal (ASBIHP)
Rua Botelho Vasconcelos
Lote 567 C/D
1900-637 Lisbon
<http://asbihp.blogspot.com>

Romania

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

Russia

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

Scotland

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

Serbia

Spina Bifida and Hydrocephalus Association of Serbia
Milesevska 40
11000 Beograd

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)
C/Pechuán 14, local 6
28002 Madrid
www.febhi.org
Associació Catalana d'Espina Bífida i Hidrocefàlia
C/Sorolla 10
Barcelona 08035
www.espinabifida.cat

Sweden

Riksförbundet för Rörelsehindrade Barn och Ungdomar (RBU)
Box 8026
104 20 Stockholm
www.rbu.se

Switzerland

Schweizerische Vereinigung Spina Bifida und Hydrocephalus (SBH)
Geschäftsstelle SBH
Schulrain 3
6276 Hohenrain
www.spina-hydro.ch

Turkey

Spina Bifida Dernegi
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
www.sbaa.org

Financial Result in 2009

Statement of the auditor

Report of the auditor on the financial statements for the year ended 31-12-2009 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 31-12-2009, prepared under the responsibility of the board of directors of the federation, which show a balance sheet total of € 463.392,97 and a loss for the year of € 39.586,23.



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 31/12/2009 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 26th 2010

BVBA De Nul & co, bedrijfsrevisor, auditor

represented by Roger De Nul

Balance sheet at 31 December 2009

Assets	31-dec-09	31-dec-08
TANGIBLE ASSETS	2.697,49	3.223,48
Investments	8.757,89	16.087,07
Depreciations investments	-6.591,19	-13.394,38
Cautions	530,79	530,79
AMOUNTS RECEIVABLE	145.780,12	83.271,18
Customers	117.714,12	36.892,02
Subsidies to receive	25.000,00	25.000,00
Others to receive	3.066,00	418,20
IF Child Help current account	0,00	20.960,96
BANK & CASH ACCOUNTS	301.077,78	268.744,29
Stocks	20.133,40	19.892,20
Bank accounts	280.944,38	248.852,09
TRANSIT ACCOUNTS	13.837,58	15.106,17
Costs for next year	13.837,58	15.106,17
Total assets	463.392,97	370.345,12

Liabilities	31-dec-09	31-dec-08
RESERVES	254.476,79	294.063,02
Funds of IF	294.063,02	294.608,40
Profit-loss bookyear	-39.586,23	-545,38
AMOUNTS PAYABLE	85.092,27	76.282,10
KBC - accounts	72,46	0,00
Suppliers	53.112,72	40.055,17
Taxes to be paid	839,00	0,00
Salaries to be paid	1.569,82	0,00
Provision holiday fee	10.038,10	7.814,83
Projects current accounts	19.280,83	28.412,10
IF Child Help current account	179,34	0,00
TRANSIT ACCOUNTS	123.823,91	0,00
Profits for next year	123.823,91	0,00
Total liabilities	463.392,97	370.345,12

Profit and loss 2009

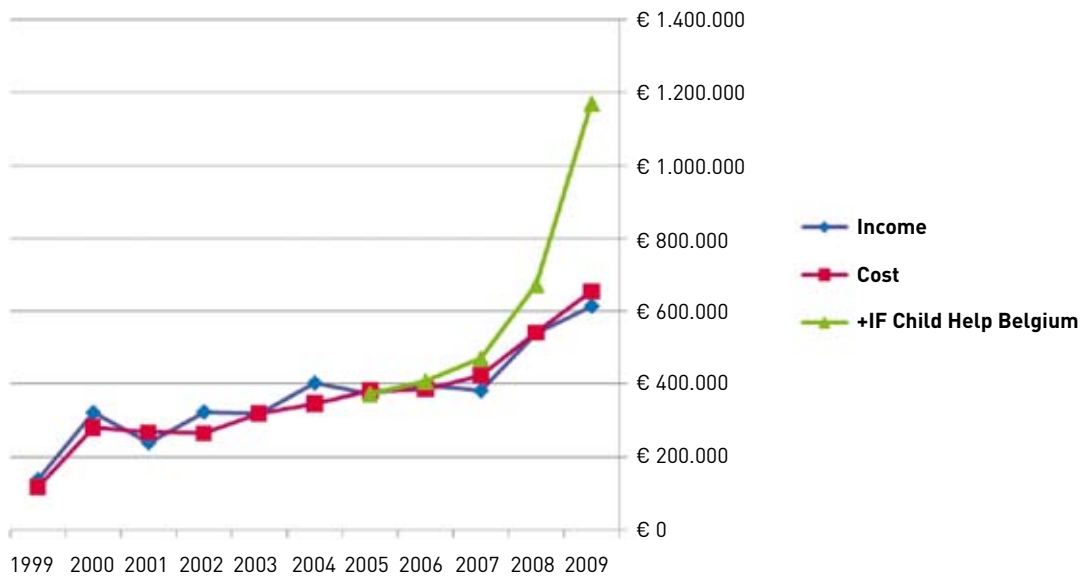
OUT	
Diverse costs	480.617,97
Housing costs	10.525,17
Office supplies	5.488,02
Publications - copy	11.632,83
Communication costs	5.420,11
Membership fees	475,00
Fee bookkeeper	3.366,43
Fee auditor	1.542,75
Other fees	36.126,16
Insurance	1.082,07
Transport expenses	67.212,39
Official documents (visas)	531,61
Representation	21.182,72
Medical material projects	75.379,23
Salaries in projects	72.046,61
Training projects	12.046,60
Other expenses projects	61.913,68
Conferences - meetings	94.646,59
Salary	164.981,02
Salary	128.061,55
Insurance staff	3.207,15
IF staff abroad	33.712,32
Depreciations	2.005,99
Depreciations	2.005,99
Financial costs	2.668,69
Bank charges	2.385,09
Payment & change differences	76,79
Change differences	206,81
Exceptional costs	4.223,57
Exceptional costs	4.223,57
Total costs	654.497,24



IF volunteer Zjuul Devens at the photo exhibition "Living with a disability in Uganda",

IN	
General income	608.834,30
Membership fees	7.400,00
Other grants	101.839,00
Subsidies project Norad	228.049,36
Subsidies project SHIA	37.270,70
Subsidies project EU-project	125.000,00
Recuperation salary costs	1.129,83
Diverse recuperation	108.145,41
Financial income	4.460,47
Financial products	3.213,32
Payment + change differences	1.247,15
Exceptional income	1.616,24
Exceptional income	1.616,24
Total income	614.911,01
Result	-39.586,23

Historical Perspective

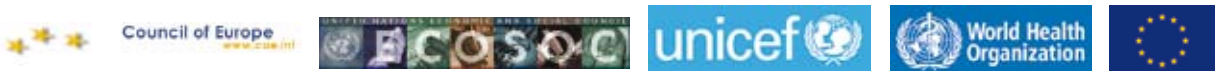




Partners

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





This publication is supported by the European Community Programme for Employment and Social Solidarity (2007-2013). This programme was established to financially support the implementation of the objectives of the European Union in the employment and social affairs area, as set out in the Social Agenda, and thereby contribute to the achievement of the Lisbon Strategy goals in these fields.

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



IF ivzw

International Federation for Spina Bifida and Hydrocephalus

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

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