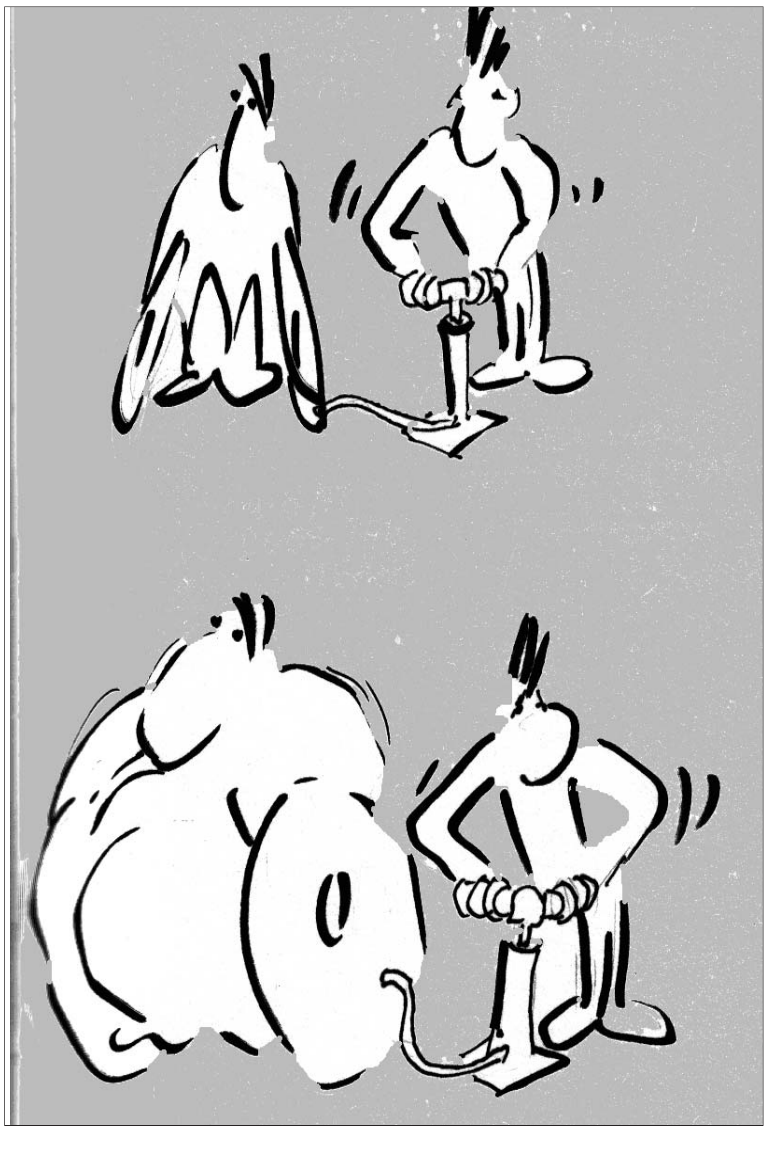
INTERNATIONAL
FEDERATION
for
SPINA BIFIDA
and
HYDROCEPHALUS

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

CROSSING BORDERS

IF ANNUAL REPORT 2004

Under the Patronage of Her Royal Highness the Princess Astrid of Belgium



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1. Looking at the same starry sky

Introduction by the President

A changing world

We live in a fast changing world in which persons with spina bifida and hydrocephalus are changing as well. They are products of their time, influenced by the attitudes in society, the medical care available, political environment, etc… Also the demography of the spina bifida and hydrocephalus population is changing. In the northern part of the world fewer children are born with spina bifida, unfortunately not only as a result of primary prevention but mostly because of termination of pregnancy when the disability is detected. Due to the improved medical care most children survive and reach adulthood. In our associations we see fewer children and a growing group of adults with spina bifida. The decrease in the North goes together with the notice of many more children with spina bifida and hydrocephalus in developing countries than was known before. Due to the development of good and affordable care in the IF projects, parents in the South look for care for their children and visit our excellent partners or contact us by the Internet. North and South are developing into two totally different directions.

Conventions versus Religion

Also world politics are changing. Religious wars have replaced territorial wars. North and South do not understand each other. Industrial countries who are defending their human rights, democracy, independent justice and individual freedom do not understand the pious fight of poor countries in the South. Very valuable conventions, resolutions, treaties and rules like the United Nations Convention on the Rights of the Child and the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities took over the moral frame work offered by religions. NGO's like Greenpeace, Handicap International, Amnesty International and IF try to kick the world's conscience. In the North, churches are nearly empty. Many philanthropic associations are closing their doors. People live together in big cities and towns but are often socially isolated. They are watching 'Neighbours' only in their favourite television soap, without having any contact in their neighbourhood and seeing their families less and less. Primetime television shows the illusion of a life without pain, without illness, disabilities or death. A world made of plastic. This evolution puts a big weight on the individual in all aspects where he is confronted with real life matters like disability. He feels alone and cannot rely on a network of family and friends because he lives in an environment that promotes perfection and hides pain, death and illness.

In the South, religion, families and neighbours are still playing an important role in the daily life of people. These treaties and conventions are far from the daily reality of a malnourished mother in Afghanistan giving birth to a child with spina bifida. CNN and the Internet could make her realize the well-being of the North but without any view of improvement of her own living conditions. Her fight to survive death is a daily reality. This plastic northern world is perceived as immoral and decadent.

Stars

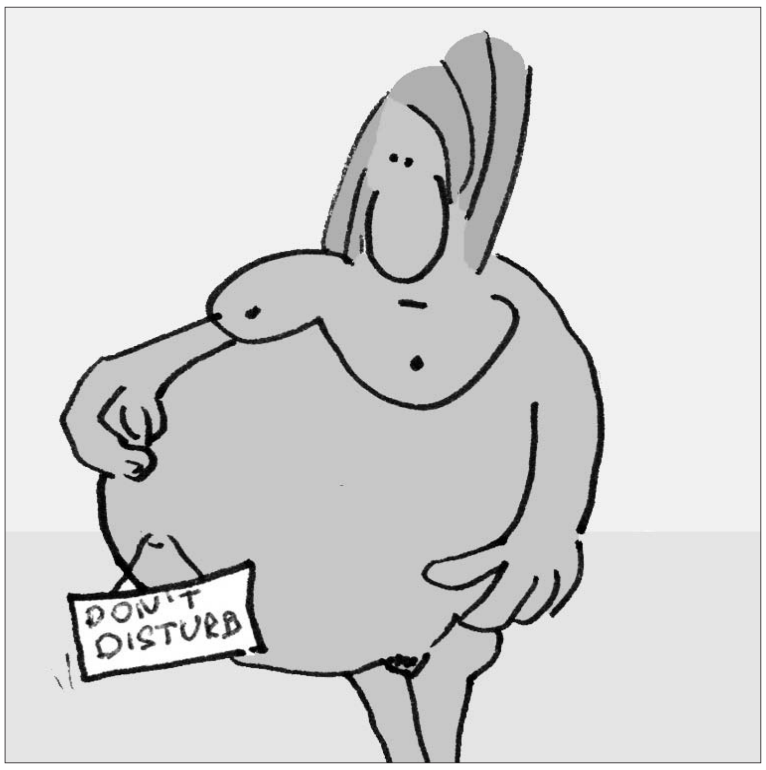
But how valuable are all these treaties and conventions for the mother of a new born child with spina bifida in Groningen, where doctors believe that the life of this child in not worth living. In Groningen doctors want to legalize the possibility to kill the child just because of his or her handicap. What can treaties do for the right of the unborn child that is different? For the wrongly informed mother who is pregnant of a child with spina bifida? The rights of women come in conflict with the rights of children. These valuable conventions regulate important values and rights but are insufficient to regulate life and death. The liberal right of free choice overpowered the right to live and the respect for all human beings.

At night both mothers are looking at the same starry sky as the soldier in Iraq or a mother with a child with spina bifida wherever in the world. Why me, why my child, what is the sense of this life, this pain. Call this sky, the universal, Allah, God, Yahweh, or nature, it is a way the individual is in contact with something bigger than his own existence. A way to search for the best, the good and to understand what is happening.

Crossing Borders

At our annual conference 2004 in Oslo 'Crossing Borders' we really listened to each other and crossed borders between religions, left and right, poor and rich, north and south, east and west. This is IF. We enhance what we have in common by sharing a problem: spina bifida and hydrocephalus. No wars and no misunderstanding, because I have more in common with this mother in Afghanistan than with the owner of the bookshop around the corner.

This intercultural view gives IF an important voice. We look at this world through the hole in the back of children. Perhaps a limited view? Undoubtedly yes, but at the same time it offers a wide view that goes beyond nationalism, religion, capitalism, and so on. Rather than investing in military hardware, misusing the name of God or Allah in wars and terrorism, the world should invest in solidarity between people with the same problems, like IF does. This will bring the North and the South closer together.
This IF solidarity between the North and the South resulted in many projects in developing countries where children get the care they deserve and where parents can meet in self supporting groups.
10 years ago IF started projects for early detection and rehabilitation in developing countries. Due to the involvement of our partners in the South, children survive and their parents and user groups are starting to organize. IF is developing a good and realistic care where the maximum is achieved with local means. IF is proud that several of its local partners are publishing their results in international medical and scientific journals. The ETV as an alternative for shunting, the IF continence management program and the IF treatment of pressure sores are now of benefit to the North as well.



IF Knowledge Centre

Associations for spina bifida and hydrocephalus now exist throughout the world building on the same two principles: contact and information. This network of knowledge is the basis of the IF Knowledge Centre which is in full development. Because of the Internet, IF can make this knowledge easily accessible and the IF Knowledge Centre aims to become a quality controlled user driven information bank. The mother in Afghanistan can help the mother in Groningen or Minneapolis. The IF website is now available in Spanish, Dutch and Portuguese, French is in the making.

Challenges

But there is still a lot to do. With the newly elected IF board, with a vice president coming from Africa and members from the Pacific, America and Europe, IF is able to face the challenges of this fast changing world.
Children with spina bifida and hydrocephalus nowadays have the same life expectancy as other kids. A large group of adults with spina bifida and hydrocephalus want to be full citizens. Expertise is missing to assist them in their specific problems and in most countries there are no interdisciplinary teams for adults.
In several countries adults with spina bifida and hydrocephalus take the lead in their associations and fight for a better life. IF welcomed a second adult with spina bifida on its Board and at our 2004 conference an adult day resulted in a vision and strategy towards adult work within IF.

Priorities

In 2004 the IF general meeting made three major priorities for the future
- The development of the IF Knowledge Centre to make knowledge available and to facilitate solidarity and cooperation.
- Primary prevention and research into the causes of spina bifida
- The professionalization of IF to ensure continuity.

Is IF a success story? Undoubtedly yes, considering that all this is done by volunteers. The biggest challenge for IF is to build on these results and maintain the input and spirit of volunteers who are themselves confronted in their lives with spina bifida and hydrocephalus. To professionalize the federation without loosing track of the target group: people with these impairments and their relatives. Nothing about us, without us. In the name of God? I prefer the starry sky, or let me just call it the thousands of dedicated people within the network of IF; what's in a name?

Pierre Mertens
President IF

2. What is Spina Bifida and what is Hydrocephalus?

What is Spina Bifida?

Spina bifida is one of the most common congenital birth defects, affecting 1 to 2 in every 1000 live births.
It is caused by a defect in the development of the central nervous system in the early stages of pregnancy and in the first 25 days after conception. The spinal cord and vertebrae do not form completely and the neural tube fails to develop normally. Because of these defects, people born with spina bifida usually have some degree of paralysis, which affects their mobility as well as their bowel and bladder control. More than 85% of babies with spina bifida also develop hydrocephalus.

People with spina bifida often need long-term care and medical follow-up. However, with proper support, most people with spina bifida learn to overcome problems, gain confidence in themselves and go on to live full and independent lives.

What is Hydrocephalus?

Cerebrospinal fluid (CSF) is produced in the ventricles or cavities of the brain. It circulates throughout the brain and spinal cord and is absorbed into the bloodstream. Normally there is a balance between the production and the absorption of CSF. If the natural circulation of CSF is obstructed, fluid accumulates in the brain and hydrocephalus results. The excess fluid presses on the brain causing damage to the surrounding tissue. With babies and infants where the skull is still soft, the head enlarges.

This obstruction of the normal CSF pathways can be caused by abnormal brain anatomy as is the case with Spina Bifida. It can also be the result of meningitis, tumours, cysts, trauma or intracranial bleeding which occurs more frequently following premature birth.

Hydrocephalus is treated surgically either by the insertion of a shunt, which is a valve and tube system, which diverts or shunts the excess CSF around the blockage so it can return to the bloodstream, or by an endoscopic third vertriculostomy (ETV) which creates a natural bypass for the CSF.

3. What is IF?

IF is a global network of people with spina bifida and/or hydrocephalus and their relatives, who co-operate worldwide. IF is the world wide umbrella organisation for these two disabilities and has developed a network of contacts on every continent. Its members are national organisations of people with spina bifida and/or hydrocephalus in more than 40 countries. These national organisations support people with spina bifida and/or hydrocephalus and their relatives in their daily lives.

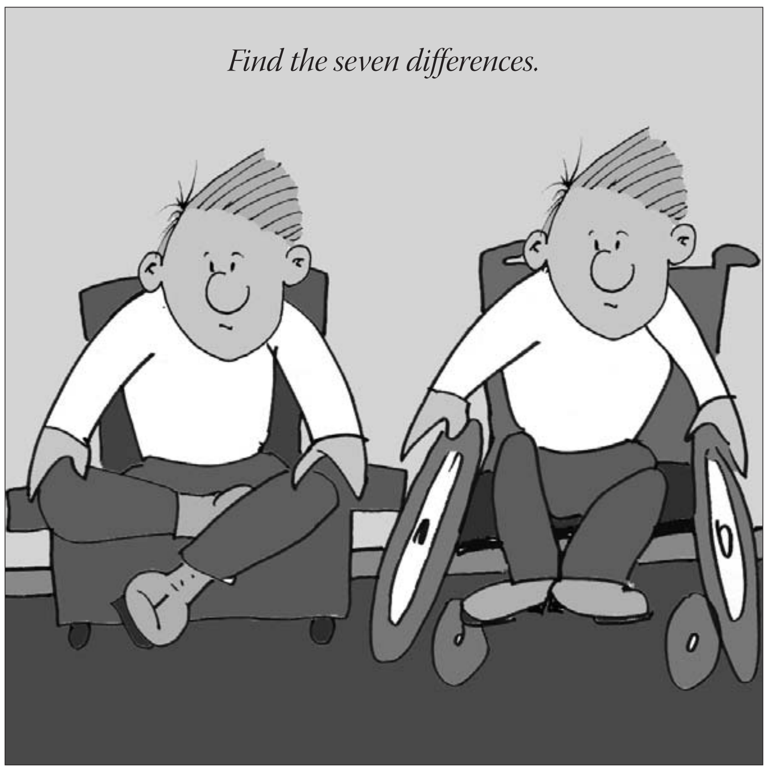
To be able to focus and highlight specific characteristics of different groups within IF, IF is made up of several divisions: based on geography and language: IF Europe, IF French division, Ibero American Division, Adult division.

IF's mission and goals

IF's mission is to improve the quality of life for people with spina bifida and/or hydrocephalus world wide and to decrease the prevalence by primary prevention.

This mission is the motivation for everything IF undertakes, and it is also shared by the IF member associations. The most important way to fulfil that mission is to spread knowledge and encourage contact between parents and people with spina bifida and/or hydrocephalus.

IF represents people with spina bifida and hydrocephalus and their organisations on a global level in other international bodies such as the United Nations, World Health Organisation, the Council of Europe, European Union, EDF, UNICEF and INGO's.



Find the seven differences.

4. The IF board of 2004-2006, staff and consultative expert team

The General Meeting elected a new Board during the Annual General Assembly in Oslo, September 2004.

We thank the members of the previous Board for their dedicated participation which contributed to de development of IF by putting emphasis on specific aspects. Kerrie Engel on adult work, Teresa Cole on adult involvement and organisation building, Runa Schøyen on development cooperation, Bo Hjelt on financial sustainability and Klaus Seidenstücker on ethics .

The IF Board

Mr Pierre Mertens, President:
Belgian nationality. Profession: visual and contextual artist.

Pierre Mertens' (°1953) first child, Lies, was born with spina bifida. For that reason he founded the Belgian Association for spina bifida and hydrocephalus. Mr. Mertens founded PHOS in Brussels, the Belgian Platform for Handicap and Developing Country Work and stepped down as President of PHOS early 2003. In 1995 he was elected President of IF. Together with his predecessor he initiated the IF projects in developing countries and still advocates solidarity between the North and the South. In 2001 he wrote a book about the birth and death of his daughter Lies. This book was translated into French, English and Norwegian.

Mr. Aloysius Bakkidde, Vice President:
Ugandan nationality. Profession: Engineer.

Aloysius Bakkidde is the father of two sons and two girls. The second youngest, Martin Antony Kizito, was born with spina bifida and hydrocephalus in September 1971, and is a wheelchair user. In 1977 Mr Bakkidde and his family moved to Kenya where he, together with other parents, started an Association of parents and teachers and became its first Chairman. In March 1993 he joined the management committee at Katalemwa Cheshire Home and became Chairman of the committee in 1993. In 2002 Mr. Bakkidde was co-opted to the IF Board and is a very active participant in nearly all activities involving people with disabilities.

Mr. Trevor Capps, Treasurer:
Australian nationality. Profession: National President of Australian Spina Bifida Hydrocephalus Association

Trevor Capps lives in Buderim in Queensland, Australia. He is happily married and has two wonderful children. He has a Bachelor's degree in Arts, a graduate diploma of Social Planning and he completed postgraduate studies with focus on Evaluation and Organizational Psychology. Currently, he is the general manager for the Spina Bifida Hydrocephalus organization in Queensland. Here he introduced appropriate budgeting and financial reporting to ensure effective governance and he renegotiated government funding to provide a better cash flow and increase services to the regional areas.

Ms. Cindy Brownstein:
American nationality.

Cindy Brownstein is the Chief Executive Officer of the Spina Bifida Association of America (www.sbaa.org) and the Spina Bifida Foundation, a sister organization. She has worked for the spina bifida community in these roles since 2000. Prior to joining SBAA and SBF, Ms. Brownstein served at the Epilepsy Foundation as Executive Vice President. During her tenure, Ms. Brownstein also functioned as the organization's interim Chief Executive Officer. Prior to joining the Epilepsy Foundation, Ms. Brownstein held the dual position of Vice President for Education and Research at the Hospital Association of New York State and Executive Director of the Hospital Educational and Research Fund, an affiliated organization. These organizations represented and advocated for the 400+ voluntary hospitals in New York State.

Mrs. Renée Höglin:
Swedish nationality. Profession: a freelance writer and journalist

Renée has a son with spina bifida and hydrocephalus. She has written three books on disability topics, among them one called "Have I Got A Chance With You?" which is now being published in Japan, plus hundreds of articles and leaflets on issues of disability. She has been a member of RBU (the Swedish umbrella organization for parents of children with mobility problems) since the mid 70's, a Stockholm Board member from 1995 – 2004 and a national Board Member since 2003. She is a member of the Spina Bifida & Hydrocephalus Committee of the national RBU together with Eva Toft and Karin Berggren. She has also been the editor of a regional RBU member magazine, Hört & Hänt, until spring this year. She wants to contribute to the IF Board with her media knowledge and communication skills and her long experience as a parent of a son with SBH. "I would like to be engaged in the research and treatment of people with spina bifida and/or hydrocephalus in member countries and particularly in Africa. Another vital issue is the transition period from teens to adulthood and how we can strengthen individuals for adult life."

Mrs. Cristina Pavisic:
Italian nationality. Profession: Chemistry teacher in a secondary school

She has a son with spina bifida and this made her understand that people in wheelchairs can still do things like everybody else. This is why for the last four years, Dr. Cristina I. Pavisic has coordinated the mobility for youth with spina bifida for the Leonardo da Vinci project in Europe. She is also the European project's coordinator for FAISBI (Italian SBH organization). "It is very important for people with disabilities to have the same opportunities as all the others, especially young people. They have to be prepared to face the future, they have to learn foreign languages and they have to be able to study or work in new environments without parents."

Mr. Jon Burke:
UK nationality. Profession: User Involvement Coordinator

Jon has spina bifida and arrested hydrocephalus, as a result of this he is a full time wheelchair user. He has 20 years of experience with working on disability issues. This includes time working for both statutory and non-statutory organizations, specializing in supporting the development of disabled people and disability organizations. Examples of this include: the development of a youth section of a national disability organization, the setting up and project management of an IT training organization for disabled people which was involved in a variety of EU funded programmes and more. He was a founder member of Your Voice, the disabled service users section of Asbah and he is the current Chair of the group. His parents were involved in the setting up of a local association for spina bifida and hydrocephalus the year after the national association was set up. He gained a degree in Politics and History in 2002 after studying for a number of years as a mature student. "I would particularly like to support the IF Boards work in developing services for people with spina bifida and/or hydrocephalus as well as helping to get more disabled service users involved in contributing to and running their own services."

Mr. Teije Dijk:
Dutch nationality.

His youngest son was born with spina bifida. Teije Dijk is director of the Service for Education, Sports, Culture, Welfare Social Care and Public Health in a municipality. He is also part-time organization-advisor for public and private institutions. Mr. Dijk is a strong advocate of implementing ethical standards when it comes to all disabilities. For years Mr. Dijk was an active member and Vice-President of the BOSK Board, the Dutch organisation for people with motor handicaps. He is still involved with the working group for spina bifida and hydrocephalus within BOSK.

Mr. Louis Quaresma:
Portuguese nationality. Profession: member of ASBIHP

Luis is an adult with spina bifida and he has worked for ASBIHP for the last 15 years and he is the President of the Board. During the last two years he has been part of the development of several projects that will contribute to the improvement of the quality of life of people with spina bifida and/or hydrocephalus. He was also a member of the CNOD (National Council for Disability) Board for 6 years and he represents ASBIHP in the Governmental Department for Disability (SNRIPD). He believes it is important to increase the variety of countries in the Board and to help the African countries so that their health care services can be improved. He also would like to trigger the interest of the young adults with spina bifida, so they can become more involved in the life of IF. "Because I am an adult with spina bifida, I think it is important to be involved in the life of the Federation and I think that with my experience. I can contribute to the good work that IF has being done.”

The IF Staff

Ms. Els De Clercq:
Developing countries project manager
Belgian Nationality

Els De Clercq is a psychologist. For many years she has been actively involved in youth organizations, completing several courses in leadership. During her studies, she received training in different branches of psychiatry for several months. On completion of her studies, she worked for one year in an organization, which specialized in raising funds for projects in developing countries. During this period she became interested in helping people in these countries. After she organized the administrative side of IF, she became project manager of the IF development cooperation projects.

Lieven Bauwens:
Project manager
Belgian Nationality

Lieven Bauwens spent a year in Iowa, US as an exchange student after his secondary education. He finished his studies in architecture in 2001. After that, he studied a Master in General Management and European Human Resource Management at the Vlerick Leuven Gent Management School for which he stayed three months in Denmark and Iceland to complete a master thesis on performance indicators for a non-profit organisation. Lieven has 2 brothers and 1 sister, of whom one brother, 19 years old, has spina bifida. After having worked for a project sponsored by the European Commission and the Flemish government concerning employment for long term unemployed and low skilled people, Lieven became a manager for a regional centre for social economy, consulting starting businesses. Lieven is also active in a movement for celiac patients and the international exchange organisation he went abroad with.

Mr. Eric Holdtgrefe:
General management, assistant to the president.
American and Dutch nationalities.

A retired (2000) senior executive of the AkzoNobel Pharma Division (ORGANON TEKNIKA). Mr. Holdtgrefe had full P&L responsibility for the OT operations in Latin America, Africa and the Middle East. In the past he was also responsible for the Asian operations (ex USA). He lived in Singapore, Colombia, Argentina and USA. After his retirement Mr. Holdtgrefe worked for the Liliane Foundation for 1.5 years after which he became involved in the management of IF. He is very much involved on the organisational side of IF including budgets and matters related to financial control. In addition, he translated the current IF website into Spanish and Dutch.

Lorraine Leeson:
Consultant to IF
Irish Nationality.

Mrs Leeson worked for the European Union for the Deaf and was responsible for the compilation of information from EU sources, including calls for proposals, and ensuring timely dissemination of this information to members. She is trained in incorporated aspects of political strategy and lobbying (Certificate in Feminism, Politics and the Economy, University College Dublin, WERRC). With IF she will focus on EU applications and foundations.

Consultative expert team of IF

Mrs. Blancquaert Sofie ; Legal and ethics consultant IF, Profession Lawyer
Mrs. Blaton Els; Technology advisor IF, Profession: Director IT Development Banking Applications
Ms. De Wit Olga; psychologist and consultant IF
Dr. Oneko Martina; Medical Consultant IF, Consultant Paediatrician/Neuropaediatrics
Mrs Vanden Abeele. Vero; Consultant IF knowledge centre
Mrs. van Mourik Marjan; IF management and fundraising consultant
Mr. Vanneste Geert; Consultant Developing Work IF
Dr. Verpoorten Carla; Medical Consultant IF, Neuro-paediatrician
Dr. Warf Benjamin C.; Medical Consultant IF, Paediatric Neurosurgeon, ABNS, ABPNS

Why are these holes not accessible?

5. *IF Knowledge Centre*

Knowledge is the first step in ensuring that people with spina bifida and/or hydrocephalus are full partners in decision making and that caregivers, professionals and people with spina bifida and/or hydrocephalus have access to the latest information. The IF Knowledge Centre is based on its unique global network. Thereby it is a user driven information bank which supports the improvement of the quality of life for people with spina bifida and/or hydrocephalus. It consists of medical, educational, social and lifestyle information, examples of good practice, prevention material etc.

a. An interactive website www.ifglobal.org and monthly newsflashes

The Internet plays a crucial role in sharing knowledge; it changes the world. Medical knowledge is no longer the exclusive domain of the doctor. Patients and doctors are becoming partners in the search for solutions.

The IF website contains details of all issues which support the improvement of the quality of life of people with spina bifida and/or hydrocephalus. It consists of medical, educational, social and lifestyle information, examples of good practice, advice on prevention etc… The IF website now has an English, Spanish, Portuguese, French and Dutch section.

The website had an average of 9.000 visits per month in 2004 and the frequency of visits is growing.

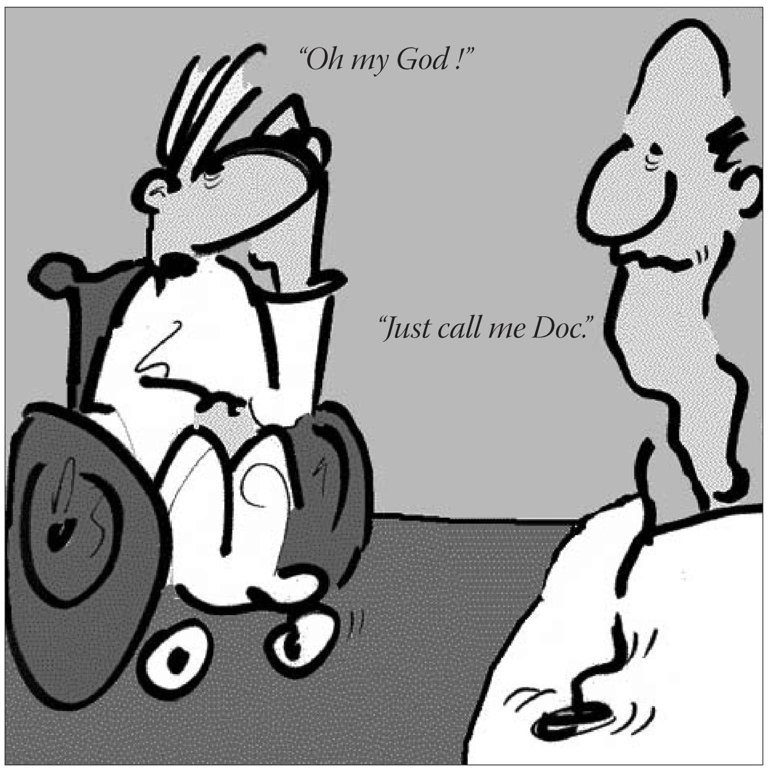
b. International conferences and workshops

The main annual IF event is the yearly conference. People with spina bifida and/or hydrocephalus and their families come together from all over the world to exchange knowledge and examples of good practice. The conferences that have taken place since IF began its activities were as follows:

1979	Stockholm (Sweden)	The family situation
1981	Dublin (Ireland)	Independent living
1983	Malaga (Spain)	Incontinence
1985	Manchester (UK)	Making our way
1987	Denver (USA)	Climb every mountain
1989	Antwerp (Belgium)	Live your life
1991	Stockholm (Sweden)	Together is strength
1993	Deinze (Belgium)	Wait a minute
1995	Sydney (Australia)	Fast forward into the future
1997	Bonn (Germany)	It's about me
1998	Washington (USA)	Celebrate the past, envision the future
1999	Perth (Australia)	A future with purpose - A future with choice
2000	Toulouse (France)	The right to be different
2001	Dar es Salaam (Tanzania)	Against all odds
2002	Warsaw (Poland)	You are my world
2003	Moshi (Tanzania)	Continence management
2004	Oslo (Norway)	Crossing Borders

Proposed Future Conferences: (* under negotiation)

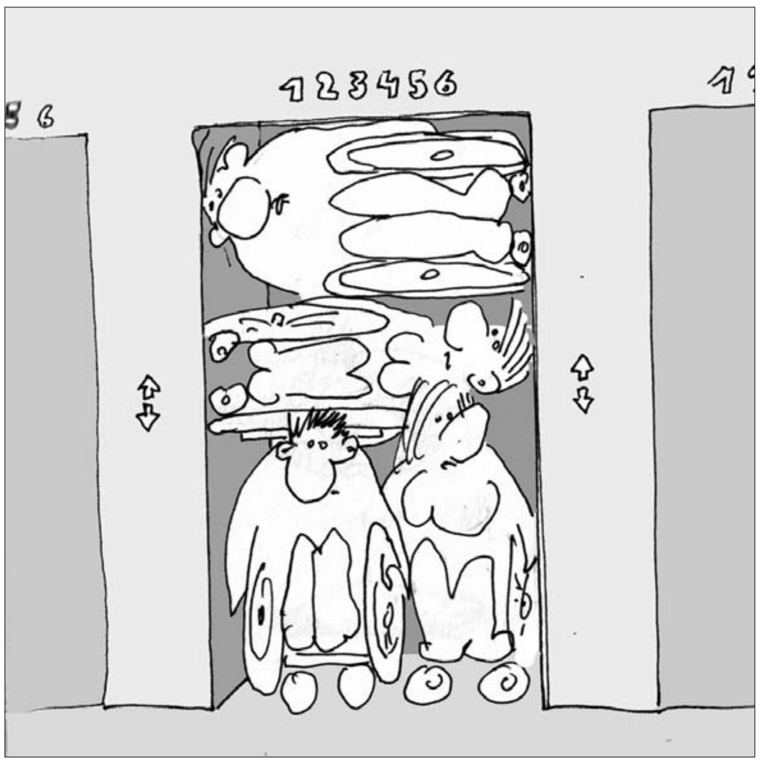
2005	Minneapolis (USA)	Building bridges to advance understanding
2006	Helsinki (Finland)	Life Course and Accessability
2007	Pacific Rim*	
2008	Portugal	
2009	Africa *	
2010	Denmark *	



I. Crossing borders, Norway September 2004

IF´s International Conference for 2004 was held in Oslo – Norway. 130 people from over 20 countries came to the conference and most of them were people with spina bifida and/or hydrocephalus or family and friends, but also professionals who work with our group participated.

"Borders and limits can be pushed, stretched, drawn out, extended and exploded, and can be crossed by the contribution of knowledge and economic help. The most difficult borders to cross are the prejudices of society and the unwillingness of the politicians to accomplish their own resolutions. We can all work on our own borders and limits, but some people need help and support to do so. The greatest challenge is to limit our own borders whilst comparing ourselves with others. Trying to achieve our goals, some borders may have to be let invisible. Remember – our dreams and fantasies have no boundaries – it is all about the quality of life" said Eli Skattebu in her opening speech.



The programme of this conference had a variety of themes: from purely medical information to dealing with the diagnosis. In Norway we focused a lot on how to handle daily life with spina bifida and/or hydrocephalus. This theme was repeated in several presentations. Some new studies on third ventriculostomy, quality of life and bowel function problems were presented. The cooperation project between IF and The Norwegian Association for spina bifida and hydrocephalus in eastern Africa was one of the main themes. A large group of people from these countries was invited to Norway and some of them had an important role in the conference.

We have met them during several days, those people from Africa who are in the same situation as we are. Our exchange of information and experiences was a real enrichment for both parties: for those of us who work with this project providing aid to developing countries, it is a challenge to impart experiences and results back home. We received a lot of positive feedback about this at the conference.

On the last day of the conference, a workshop only for adults with spina bifida and/or hydrocephalus was arranged for the first time. We hope that the group of adults, that is constantly growing, will be active in the work of IF. The themes of this workshop were interchange of experiences about how this group of adults is included in the associations in the different countries, cooperation between countries and professional life/work. The workshop benefited from the fact that the large group of participants live with either spina bifida and/or hydrocephalus.

Pierre Mertens, the president of IF, said in his closing speech: "For the first time we have had an international conference that has brought the whole world closer together. We have been crossing borders that make the distance between parts of the world and cultures smaller".

Report by the Norwegian Association for Spina Bifida and Hydrocephalus

II. First IF adult workshop, September 2004

The first IF adult workshop was being held on the last day of the "Crossing Borders Conference" in Oslo September 2004.

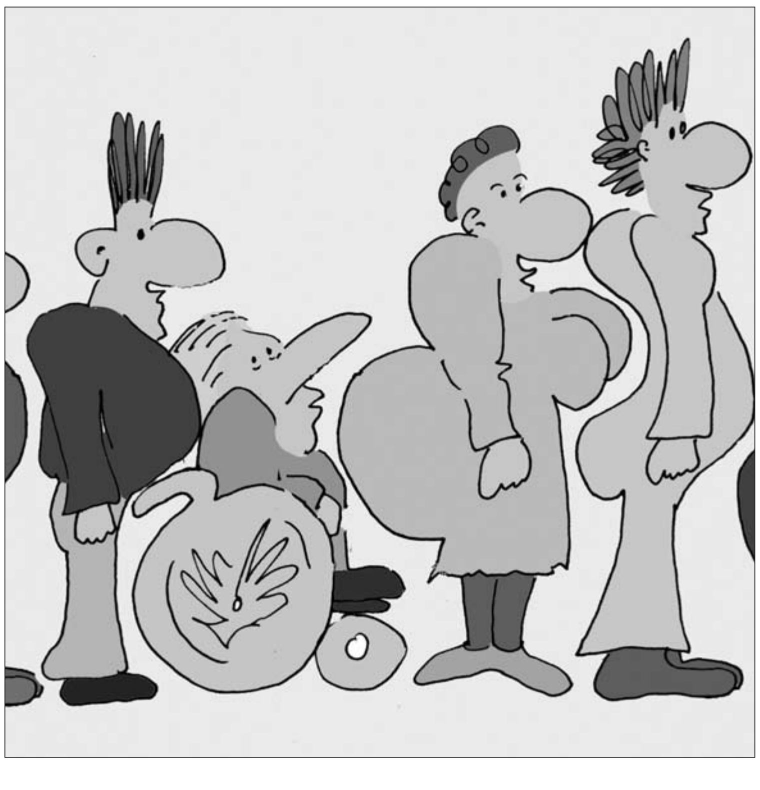
About 50 people from 21 different countries attended the workshop. The age group included teenagers; retirees who all came from varied backgrounds. About 30 of these individuals were actively involved in local, national or even international levels.

The three objectives of this workshop were: 1: to bring together adults from different countries in order to share stories, experiences, wisdoms and new ideas. 2: to create a network for communicating, sharing of information and the fostering of an international voice on matters of concern for adults with SBH. 3: Discuss adult involvement in IF.

The topics discussed included adult involvement at different levels and specifically, their situations and experiences in different countries and a draft policy document on adult involvement. The second part focused on partnerships between nations and the link to earlier conference sessions. More specifically they included topics like personal benefits for a person with spina bifida and hydrocephalus, new international partnerships of "adults for adults", why adults should become involved, the living experience, social action, capacity building and rights and responsibilities. There was a session dealing with the difficulties in becoming organized and the availability of resources. It appears that there is little information about adults with spina bifida and hydrocephalus.

The adult workshop commented on the IF policy statement on adult involvement requesting a stronger commitment to include adults in the IF work and structures.

Education and employment also were issues which were discussed. The most experienced people at the workshop, Runa Schøyen (Norway) and Kristin Edwardsen (Norway) and Hild Sommerstad Bjoersvik (Norway) were the prime sources of information.



The appropriate question after the workshop is: "Where do we go from here?" Allow us to summarize the action statements:
- Distribute guest speaker and workshop information to those present
- Collate all feedback on the Policy Document
- Establish workgroups to continue to work on this and other ideas, so further progress can be achieved.
- Establish a small network of interested adults
- Explore website and forum opportunities
- Continue with personal portrait and video collecting, to be ready for 2005.

The general comments made at the workshop were:
- Hold workshop prior to the conference rather than at the end
- Should remain for adults only- despite the reverse discrimination label
- The format used in Oslo worked well
- Language is not a big problem
- Broad spectrum of adults were represented

Words of Wisdom from Oslo 2004.
- “Anything is possible, it only may take a little longer to accomplish”
- “You are the perception you have of yourself”
- “The only real disability any person has is the one in our mind”
- “We don’t search for Quality of Life, We Create It.!!!”

Report by Kerry Duff, Sonya Dennis and Eli Skattebu.

III. African Workshop on hydrocephalus, Uganda November 2004

The 2004 IF African workshop on hydrocephalus was held in Mbale, Uganda from 18 till 20 November. The workshop was attended by 115 participants from 13 different countries and parent representatives from most IF run projects. The theme of the workshop was “hydrocephalus, surgery and further care of the development of the child” and focused not only on the surgical and medical part but mainly on rehabilitation of the child. The workshop was organised in cooperation with the CURE Children’s Hospital in Mbale.

In his opening speech, Pierre Mertens referred to the IF Knowledge Centre, a network of all people involved in the world of spina bifida and hydrocephalus. He invited all persons with spina bifida, their parents, nurses, surgeons, paediatricians, urologists and pharmacists to work together to achieve and collect results. He said: “Knowledge on hydrocephalus from north to south, from east to west, from all over the world is scattered, splintered and often hidden in little corners, huts, clean laboratories, operating theatres, scientific publications, or high in the mountains of Afghanistan. IF aims to bring this knowledge together as the major mission of the organisation.”

Participants focused on the rehabilitative care of the child, through different lectures on hydrocephalus, early stimulation of the physical abilities and cognitive functions of the child and workshop sessions on long term follow up, wound care, head measurement etc.

Dr Ben Warf did an impressive job by introducing about 20 African surgeons to good shunting and ETV in separate specialised sessions. Knowledge was shared and taken back home to other service centres.

Parents, children and adults with spina bifida and hydrocephalus deserve the right treatment, at the right time, in the right place. The IF workshops in Africa are a platform for collecting and sharing this knowledge and expertise, and the unique interaction between health care workers and users, gives an added value in this process.

We specifically thank the Children’s Hospital in Mbale, Dr Ben Warf, all lecturers and all participants for making this workshop such a great success.

IV. workshop on quality of life and ethics in new European countries

Supported by the European Union (budget line ‘Youth, Civil Society, Communication’), IF has worked out a project to continue and monitor the ethical discussion on prenatal selection in all European countries and specifically initiate the discussion in the new European Member States, involving the spina bifida and/or hydrocephalus user groups network towards legislative reflection and action. In a first workshop in September 2004 in Oslo a questionnaire was presented about all aspects of the discussion. This questionnaire was discussed and filled in by a group of parents, adults with spina bifida and professionals at their national level.

The results will be discussed in a workshop in May 2005 which will map the actual political and ethical situation in the Europe, including the new member States. It will also highlight all actors and factors in the ethical discussion and select examples of good practice on national and European levels.

6. Ethics and human rights

a. The right to be different

In many countries most unborn children with hydrocephalus and/or spina bifida are detected during pregnancy by an ultrasound scan. Some people openly state that people with a disability should not exist and that the “problem” can be solved by terminating the pregnancy. In the Netherlands, a group of Medical doctors even want the right to terminate life at birth when the unborn child has a severe spina bifida. 22 cases of termination after birth were documented and all of them had spina bifida.

In this debate spina bifida and hydrocephalus are mostly mentioned at the example where expected quality of life is poor and termination acceptable. Even now the medical world still speaks about spina bifida and hydrocephalus in terms of ‘”useless existence” and “lifelong unbearable pain,” and “treatment would even be unwanted and dangerous.” This makes IF and its members important partners in this debate. In the international disability movement IF took the lead in creating awareness on the subject.

During the past eight years, IF has been studying this matter in close consultation with its members and assisted by prominent experts.
At the 12th International Conference for Spina Bifida and Hydrocephalus of IF in Toulouse in 2000, a resolution ‘the right to be different’ emphasized the right to live of people with Spina Bifida and/or Hydrocephalus. Based on this resolution, IF worked together with the Human Right committee of the European Disability forum (EDF) on a European resolution on prenatal diagnosis and termination of pregnancy for all disabilities. This resolution was unanimously accepted at the EDF General Meeting in Athens in 2003. IF is preparing a statement on late termination of pregnancy directed at the UN. Through EDF IF is striving to include ‘right to life’ in the Draft UN Convention on right of People with a disability.

In November 2004 Trevor Capps represented IF at the International Bioethics Conference in Australia

b. Human rights of people with a Disability

Standard Rules for People with a Disability
“A society open and accessible to all” is the background and goal for the United Nations Standard Rules on Equalization of Opportunities for Persons with Disabilities.
These Standard rules have been written specifically to be used by disabled people. It is therefore essential that disabled people themselves ensure the Rules' effective promotion. IF uses these Rules as an important public awareness tool in its fight to represent people with spina bifida and/or hydrocephalus worldwide.

European Rules for People with a Disability
The European Union has long been involved in the fight against discrimination on grounds of gender and nationality, especially in the labor market field. Article 13 of the Treaty establishing the European Community enabled the community to combat discrimination on a wider range of grounds than ever before – disability, racial and ethnic origin, religion and belief, age and sexual orientation- and in areas outside of employment. The Community’s legislative framework now includes two important directives. The two directives lay down standards which will provide a common level of protection against discrimination across the Union and which will require changes to the existing legislative framework in all Member states.
By helping to eliminate discrimination and promote equal opportunities, the Union contributes actively to the protection of fundamental rights and freedoms and to reducing the human and financial costs of exclusion.

Draft UN Convention on right of People with a Disability
There are only UN 7 conventions who are binding governments They also cover people with a disability but they not mentioned as a specific group. Only ‘the right of the children’ has specific articles on children with disabilities. IF supports the idea of a specific convention to safeguard the rights of all people with a disability. IF as a full member and as an active partner EDF is able to have influence so that specific needs of persons with spina bifida and hydrocephalus are taken into account.

7. Prevention and Food Fortification

Folic Acid (a B-vitamin) is a simple, inexpensive supplement which reduces the incidence of neural tube defects (NTDs) in the foetus if taken by women prior to conception and for the first three months of pregnancy. IF and its members have promoted folic acid for years as the best way of primary prevention for all women of childbearing age. A much discussed problem is whether this important folic acid supplementation should be provided by food fortification.

IF and its members are closely following and lobbying to influence the recent developments in food fortification on national and international levels. IF is working with its members on a statement regarding food fortification and encourages further research on the effects of same. In 2004 Andrew Russel, director of the UK spina bifida organisation and the IF president attended the International Flour Fortification Initiative (FFI) Leadership Group in London and worked out a plan with Godfrey P. Oakley, Jr. MD, MSPM Research Professor of Epidemiology to promote Food Fortification in flour world wide.

IF also stimulates research on other influences and causes on the incidence of spina bifida. The influence of pollution (dioxin) and food affected by fungus needs further investigation.

8. Development cooperation

A decade ago, IF started its own projects in developing countries. From a solidarity point of view, IF sees it as an obligation to look beyond borders. Children with a disability are not a priority in the South. The same is true as far as developmental work is concerned. It is an ongoing process in which IF is trying to translate the latest knowledge of the North into realistic care for the South. Already now, some of the IF projects are developing research programmes which will benefit people with spina bifida and/or hydrocephalus in the South as well as the North.

The aims of the IF projects in the South are:

- Improve the basic local conditions for the treatment and rehabilitation of children with Spina Bifida and Hydrocephalus, by translating medical knowledge into realistic and affordable care in the local project and by ongoing training on all levels.
- capacity building of parents: empowerment of groups of people with spina bifida and hydrocephalus in the South and the formation of parents' groups in order to build independent parents' associations in the future, step by step
- 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

To reach its goals, IF works closely with other NGO's like CBM, Cheshire Homes, Cure, Paz-Holandesa and Lilianefonds. This cooperation in the field as well on a global level is essential for our target group and of benefit to all INGO's. Together we are stronger!

Major partners in Africa:
Dar es Salaam (Tanzania): CCBRT Disability Hospital
Moshi (Tanzania): CCBRT CBR Kilimanjaro in cooperation with KCMC (Kilimanjaro Christian Medical Centre)
Kijabe (Kenya): AIC Bethany Children's Hospital
Kampala (Uganda): Cheshire Homes Kampala
Mbale (Uganda): Children's Hospital Uganda
Lusaka (Zambia): CBR Cheshire Homes
Blantyre (Malawi): Queen Elisabeth General Hospital
Khartoum (Sudan): Cheshire Homes Khartoum

Tangible results of the project in 2004

- During 2004 the number of children followed up by the different projects reached 3000.
In the different project more then 2250 children with hydrocephalus have been followed this year and 1330 received a shunt. Over 450 children with Hydrocephalus have been helped using the ETV method. 370 new children with spina bifida are in follow up and 275 celes were closed. Over 220 children with neurogenic bladder malfunction are in CIC follow up

- The IF programme translates with the support if its medical advisors, existing medical knowledge into sustainable, realistic and payable medical care in the local setting of the projects. 2 examples are the use of the Chhabra shunt and the introduction of the neurogenic bladder programme.

- The protocol for the neurogenic bladder management has now been introduced in all projects. Intravesical oxybutinine has been introduced in all projects: intravesical oxybutinine has not only less side effects, but is 10 times more cheaper then the oral version. Projects have received extra training of local staff and training exchange programme between projects has been set up.

- Research: the Journal for Paediatric Neurosurgery accepted two articles written by Dr. Warf (published in 2005). One study outlines the results using ETV as the method of treatment for children with Hydrocephalus. A second study compares the expensive Codman shunt with the much less expensive Indian Chhabra shunt. This study shows that the Chhabra shunt performed as well as the Codman shunt. IF has been promoting the use of Chhabra shunts since the beginning of its projects in East-Africa. Not only the price played a role, but also the conviction of the equal quality, which now has been scientifically proven. The use of these substantially cheaper shunts has positive effects for many services in developing countries.

- Participation of parents in the projects: all partners and projects organised meetings with parents, often connected to clinics for follow up of the children. These parent meetings are a forum for the exchange of information and experiences, for discussion and for feedback to the local team of professionals. Representatives from parent groups are being involved in the IF African workshops.

- IF organised an African workshop on “hydrocephalus, surgery and further care of the development of the child” in Mbale. 115 participants from 13 different countries and parent representatives from most IF run projects attended the workshop. Dr Warf introducing about 20 African surgeons to good shunting and ETV in separate specialised sessions.

- Development of teaching material: a teaching video on continence management adapted to the local circumstances has been produced and shared with the projects. The available teaching material has been evaluated by the users (parents and health care workers) and will be further developed and adapted to the local situation.

- IF facilitates training necessary to run specific projects. IF already engages medical doctors, Spina Bifida nurses, incontinence nurses, neurosurgeons and paediatricians and all of these people received specific training. The project stimulates South-South exchanges for training and several projects pass on their expertise to other projects. IF welcomes and supports the Cure international initiative of a long term sustainable training programme for neurosurgery, the so called PATH programme (Programme Advanced Training Hydrocephalus) which will benefit thousands of children with spina bifida and hydrocephalus in developing countries

Funding and financial sustainability

The major part of IF’s work in Developing Countries is being funded by NORAD, through the Atlas Alliance in co-operation with the Norwegian Association for Spina Bifida and Hydrocephalus (Ryggmargsbrokk- og Hydrocephalusforeningen). SHIA/SIDA is contributing to the incontinence project in Developing Countries through the Swedish members association RBU. Medtronic Foundation has been supporting a two year project on incontinence management in developing countries.

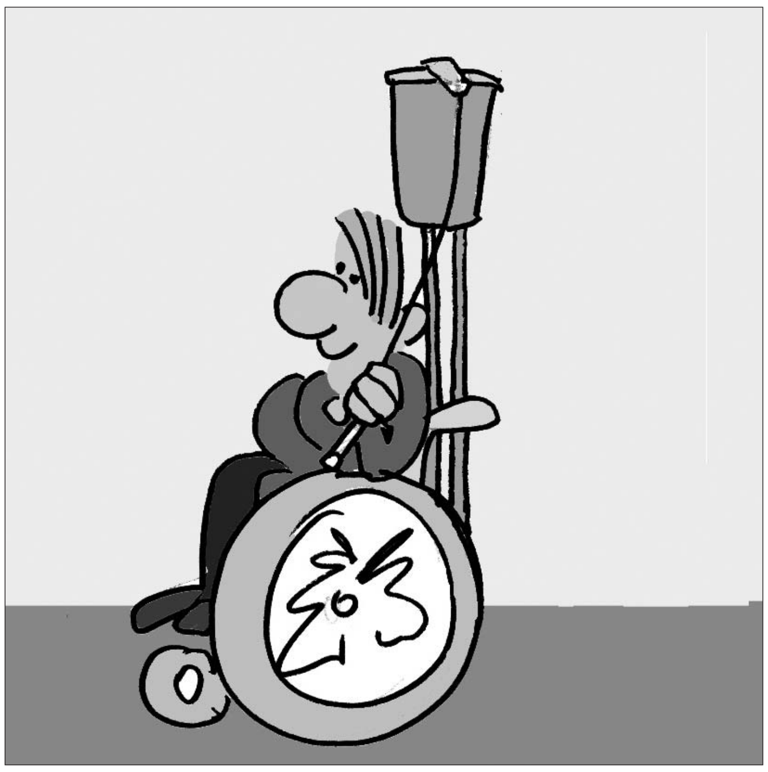
To ensure a long term financial sustainability of the IF projects in developing countries, IF is preparing applications to receive funds from other countries and is currently in negotiation with the European Commission.

Now Amina can go out, a story from Dar es Salaam.

Amina is one of many children in East Africa who has benefited immensely by the catheterisation programme introduced by IF. Being socially continent today, she is accepted by other children. Before she wasn't. This is her story.

Amina Alawi is nearly six years old and lives in a shanty town in Mazeze, a suburb of Dar Es Salaam, together with her mother, father and younger brother. Amina has meningomyelocele.

The small house surrounding an inner courtyard is also inhabited by Amina’s maternal aunt, paternal grandmother and six of her father’s siblings with their families. Amina can walk almost without difficulty, but she has had serious continence problems. Now this has changed. She has been catheterised for almost three years. At first by her mother, now she does it almost on her own
“That’s the best thing that’s happened to her,” says Hidaja, her mother. “Before we started to



catheterise I was forever washing. We could hardly go out, because her clothes got soaking wet, and I didn't dare thinking of having another baby. How could I find time for looking after a second child. But everything changed when she was able to keep dry for four or five hours at a time. Previously she had infections and fevers, we had to get her expensive medicines and I was always worried. The next target in Amina's treatment is to find a safe method of controlling her bowels. This will be done at the Disability Hospital in Dar, a modern hospital run by Comprehensive Community Based Rehabilitation in Tanzania, where Amina and her mother are getting the medical and social support they need.

Hidaja, or Mama Amina, is a facilitator to other parents. She organises a small income-earning scheme for mothers by distributing wool which they turn into tablecloths. They meet at the hospital when it's reception time for children with meningomyelocele. "We compare notes about our children and exchange hints," she says. "I tell them to listen carefully to what the doctors say, instead of just asking for medicines and believing the children will get well. If our children are to be dry, we must follow the instructions about cleanliness, rinsing the catheter and sticking to the evacuation times. Other people think Amina is fine. Seeing her encourages them to learn about catheterisation and to hope that their children can by dry as well. We have a parents' group, just a few of us, and want to put it on a more permanent footing. Then we can arrange child supervision and schooling, get assistive devices and medicines, and lobby the authorities.
I'm very proud of Amina, but to my mother-in-law she's something evil, a punishment. My husband accepts her, though I have to take care of everything, visits to hospital included. Next year I hope Amina can start school very near home."

And what does Amina herself have to say? What difference has it made, being able to manage the catheter herself? "I don't wet myself. It's a good thing, being able to pass water by yourself. Now I can go to school and learn to read and write. Mother wants me to be a doctor and help other children who are like me."

Written by Renée Höglin

9. IF Award 2004

Every year, the International Federation for Spina Bifida and Hydrocephalus (IF) presents the IF Award to an individual or organisation in recognition of the special contribution they have made in the service of people with disabilities in general or to people with Spina Bifida and/or Hydrocephalus in particular. The award itself is a small bronze sculpture. It was designed and created for IF by the Swedish artist Mr. Olovson.

In previous years IF awards were given to Jim Begg (USA), Mami Kawasaki (Japan), Hans Hoegh (Switzerland), Carla Verpoorten (Belgium), Björn Rundström (Sweden) and Geert Vanneste (Tanzania).

The IF Award for the year 2004 was presented to the Ryggmargsbrokk- og Hydrocephalusforeningen by unanimous decision of the international Board. Ryggmargsbrokk- og Hydrocephalusforeningen is the Norwegian association for Spina Bifida and Hydrocephalus.
The Norwegian association has achieved wonderful results in their own country including playing a leading role in establishing the centre TRS. From the beginning, the excellent work carried out in Norway has been shared with the international community, by playing an important role in our federation. Otto and Mona Berg and more recently Runa Schøyen have been active members of the IF board. On the establishment of the IF projects in developing countries the Ryggmargsbrokk- og Hydrocephalusforeningen showed their solidarity immediately, not only with fundraising campaigns, but also the lobbying of their government agencies, Norad, and Atlas Alliance, which resulted in the financial input IF needed to succeed in this new challenge. The Norwegian association was closely involved in the entire process and motivated African parent groups to grow and fight together for their children. The whole association supported African solidarity and many of their members are involved in training and exchange projects in East Africa. As far as we are aware, Ryggmargsbrokk- og Hydrocephalusforeningen was the first member country to elect an adult with spina bifida to lead their association - another progressive act which has been an example for others world wide. With this award, IF expresses its great appreciation for the work done by Ryggmargsbrokk- og Hydrocephalusforeningen in improving the lives of many children and adults with hydrocephalus and spina bifida in Norway, in Africa and world wide, and wishes them well in the next phase of their valuable work, as they move into their new premises.

10. Financial report IF

accounts 2004

Balance 31 December 2004
- amount in €

Assets	**31-dec-04**	**31-dec-03**	**Liabilities**	**31-dec-04**	**31-dec-03**
TANGIBLE ASSETS	**4.865,58**	**0,00**	**RESERVES**	**333.947,77**	**271.363,65**
Investments	7.298,00	0,00	Subscripted capital	82.994,30	82.994,30
Depreciations investments	-2.432,42	0,00	Profit-losses reported	188.369,35	122.390,62
			Profit-loss book year	62.584,12	65.978,73
AMOUNTS RECEIVABLE	**19.764,71**	**16.574,86**	**AMOUNTS PAYABLE**	**40.479,37**	**13.800,91**
Customers	3.837,66	437,13	Suppliers	35.479,08	6.013,74
Advances projects	15.927,05	16.137,73	Invoices to receive	0,00	7.787,17
			Provision holiday fee	5.000,29	0,00
BANK & CASH ACCOUNTS	**364.781,69**	**268.221,40**			
Stocks	117.772,48	0,00			
KBC - accounts	148.590,97	147.254,27			
KBC - accounts saving	98.221,85	120.772,83			
Cash accounts	196,39	194,30			
TRANSIT ACCOUNTS	**275,93**	**368,30**	**TRANSIT ACCOUNTS**	**15.260,77**	**0,00**
Costs for next year	275,93	368,30	Profits for next year	15.260,77	0,00
Total assets	**389.687,91**	**285.164,56**	**Total liabilities**	**389.687,91**	**285.164,56**

Profit and loss 2004
- amount in €

Costs		
	Rent office and office supplies	13.338,24
	Public relations/fundraising	8.542,97
	Website - telephone - fax – mail- postal costs	7.623,24
	Fees	6.803,19
	(translator, bookkeeper, auditor, social secretary, medical secretary)	
	Insurances	367,45
	Representation and membership to organisations	7.327,58
	Conferences and working meetings	28.141,28
	Cost for the projects in developing countries	187.550,03
	Salaries	69.789,58
	Depreciations	2.432,42
	Diverse taxes	0,00
	Financial costs	10.176,78
	Exceptional costs	4.653,98
Total costs		**346.746,74**
Income		
	Membership fees	3.090,00
	Subsidies projects developing countries	281.023,85
	Subsidies project Ethics	30.200,00
	Donations and fundraising	45.177,49
	Activities - Liesje Mertens Fonds	7.582,50
	Activities - Friends of IF	6.195,00
	Donations through KBS	15.500,00
	Diverse recuperation	10.433,11
	Financial income	8.582,25
	Exceptional income	1.546,66
Total income		**409.330,86**
Positive result		**62.584,12**

11. Report from the Auditor

In accordance with the assignment by the board of directors, we hereby report about the audit assignment which we were entrusted with.

We have carried out the audit of the annual account, prepared under the responsibility of the board of directors of the federation for the financial year of 2004, closed off on 31/12/2004, with a balance sheet total of 389.687,91 and a profit and loss account with a bonus of € 62.584,12 for the financial year. We also carried out the specific additional audits which are required by law.

Unqualified audit opinion on the financial statements
Our audits were carried out in accordance with the standards of the Institute of Enterprise Auditors [Instituut der bedrijfsrevisoren/Institut des Reviseurs d'Entreprises]. These professional standards require that our audit is organised and executed in such a way that a reasonable degree of certainty is obtained that there are no vital inaccuracies in the annual accounts, taking into account the Belgian legal and administrative law provisions.

In accordance with these standards we have taken into account the administrative and accounting organisation of the federation, as well as the internal audit procedures. The people from the federation who are responsible have replied clearly to our demands for clarification or information.
On the basis of random sample surveys we have investigated the justification for the amounts included in the annual accounts. We have assessed the valuation rules, the significant accounting estimates which the enterprise made and the presentation of the annual accounts as a whole.
We feel that this work forms a reasonable basis for making our judgement.

In our opinion, taking into account the legal and administrative law provisions applicable, the annual accounts rounded off on 31/12/2004 present fairly the financial position and the results of its operations for the year then ended.

Additional Statements

We supplement our report with the following additional statements which do not impact on our audit opinion on the financial statements :

- Without prejudice to certain formal aspects of minor importance, the accounts are kept in accordance with the legal and administrative law provisions applicable in Belgium.

- We do not have to inform you of any action or decision which has been made or taken in violation of the articles of association or the Law on International Non-Profit Organisations. The result which will be presented to the general meeting is in accordance with the legal and statutory provisions.

Lennik, February 25th 2005
BVBA De Nul & co, bedrijfsrevisor (enterprise auditor)
represented by Roger De Nul, Legal Auditor

12. Acknowledgements and thanks to the donors

Of course, none of this important work would have been possible without the generous support of so many people and organisations, and we therefore would like to express our special thanks and appreciation to those who supported us financially and physically. For the day-to-day business of the Board and its meetings we have been indebted to national organisations that have paid the travelling costs for a member of the Board.

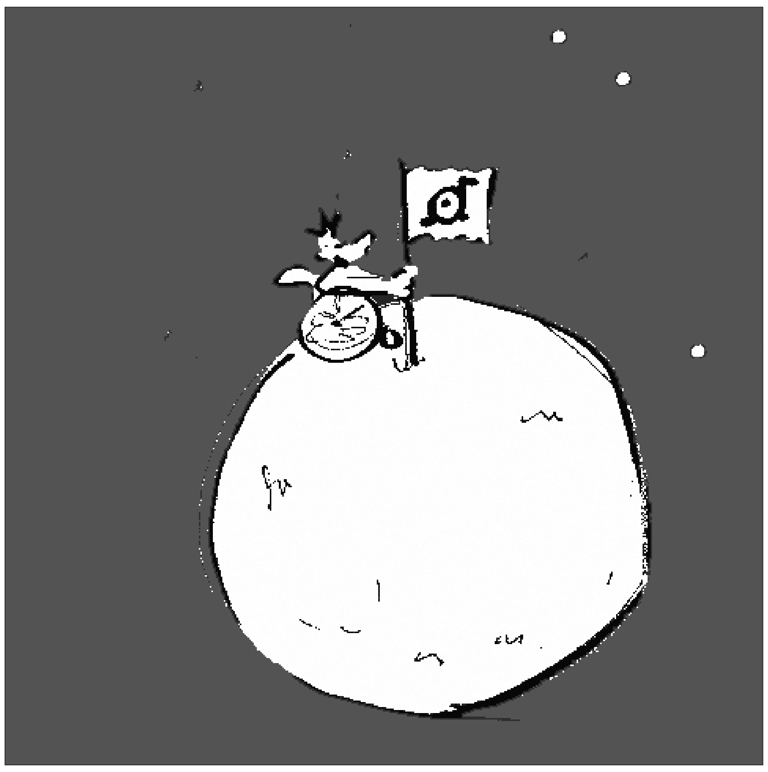
NORAD through the Atlas Alliance in co-operation with Ryggmargsbrokk- og Hydrocephalusforeningen, the Norwegian Association for Spina Bifida and Hydrocephalus, are funding the major part of our work in Developing Countries. Since 2003, SHIA/SIDA is contributing to the incontinence project in Developing Countries through the Swedish daughter association RBU. Medtronic's is supporting a two year project on incontinence management.

The EU and Oever, a cooperative of congregations in Flanders, supports the Ethical project in new Accessed EU countries.

Many thanks also to the following sponsoring initiatives from IF sympathisers: the Liesje Mertens Fonds, the Friends of IF, Ladies circle 51, Rotary Bonheiden Raambeek (B), Municipality Eeklo (B) and the Municipality Lochristi (B).

Other donations such as those of our Support Members are too numerous to mention but have helped us to respond quickly to requests for help and information from all continents.

All donors, large or small, are given regular reports on our work and projects, which would not be possible without them.



And last but not least, IF wishes to thank its many volunteers, without whom this work would not have been possible:
Baroch Tom for advise in the Election Committee
Begg Jim from the Dentsu BLD group
Blanquaert Sofie for advice on ethical and juridical questions
Blaton Els for supervision IF–Knowledge Centre
Cole Teresa for advise in the Election Committee
De Greeve Gilbert concert Liesje Mertens Fonds
De Greveleer Patrick from the Dentsu BLD group
De Schutter Anna for data management
Devens Zjuul for photography and camera work
Devlieger Patrick for advice on research projects
De Wit Olga representation IF – Europe in EDF and the European disability parliament and Working group on ethics
Eskes Tom for advice on prevention
Maitreau Antoine en Catherine for language control
Melis Anna concert Liesje Mertens Fonds
Mertens Marianne for translation French
Mertens Leen en Raes Tom for the Liesje Mertens Fonds
Mertens Charles for advice staff administration
Gillis Philppe for medical advice and training in the South
Hauters Vero for the development of the IF Knowledge Centre
Hjelt Bo for the management and election committee
Kerstin Hjelt for the Friends of IF and logistic support on congresses
Holdtgrefe Eric for assistance to the president and Spanish contacts
Leyssens Werner for legal advice
Joniaux Lieven for advice on EU dossiers
Lieben Marie-Elise concert Liesje Mertens Fonds
Oyen Marleen Liesje Mertens Fonds
Pellens Paul Liesje Mertens Fonds
Putseys Tom for advice on software and development website
Raeymaeckers Mol
RBU and especially the spina bifida and hydrocephalus group with Karin Berggren, Höglin Renée, Toft Eva and Rundström Bjorn for the commitment in the work on development cooperation and the contact with SHIA
Ryggmargsbrokk- og Hydrocephalusforeningen for the organisation of the 2004 conference and especially Lovik Njaal, Schøyen Runa, Skattebu Eli and Spiten Ann Eli for the commitment in the work on development cooperation and the contact with Atlas.
Sarsfield-Keily Phillippa Friends of IF and language control
Van Mourik Marjan for management and fundraising advice
Verpoorten Carla for medical advice and training in the South

All volunteers who are dedicated to our target group on local, national and international level and all the co-operators of the IF-projects worldwide and Her Royal Highness the Princess Astrid of Belgium as IF Patron

All of these people are valued supporters of this vital work. We look forward to a future in which we can count on their continued interest and financial backing.

Colofon
Text : Pierre Mertens, Eric Holdtgrefe, Els De Clercq, Renée Höglin, Kerry Duff, Sonya Dennis and Eli Skattebu and the Norwegian association for spina bifida and/or hydrocephalus
Language control: Eric Holdtgrefe
Photo: Zjuul Devens, IF
Drawings: Pierre Mertens
Legally Responsible: Pierre Mertens

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