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# Building Bridges Annual Report IF 2005

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# 1 Spina Bifida - should we make it sexier?

Most people with Spina Bifida still require lifelong care. However, if they get enough encouragement and are given opportunities, their self confidence grows, they can overcome most problems, they build a meaningful and independent life. Through the IF network they find the right solutions. In 2005, many attended the excellent Minneapolis conference or the African workshop in Nairobi on parent groups.

The treatment of Spina Bifida for children and adults has improved tremendously during the past decade, mostly through the hard work of many individuals. Devoted people within the IF network contributed to effective continence management equally applicable in the North as in the South and avoiding unnecessary surgery. In Minneapolis, Dr Ben Warf, the American pediatric neurosurgeon working in Uganda, received the IF-award for the great progress he made in treating hydrocephalus without using shunts. Because of all this, the quality of life for people with Spina Bifida and Hydrocephalus was improved again.

Most people with Spina Bifida study, work, have children of their own and grow old. Also within the IF network, they become members of boards of trustees and several have become leaders of an organisation. The IF network includes several physicians, lawyers, musicians and even an ex-minister. All of them have serious forms of Spina Bifida. Undoubtedly this is the result of good co-operation between people with Spina Bifida, their parents, physicians and the associations in the various countries of the IF-network.

More and more the worldwide IF network of knowledge is guided and managed by people who have these impairments themselves. But the IF network is not a closed group because they accept everybody who can contribute to a better quality of life, including dedicated nurses, physicians, technicians, professors, architects, commercial entities, governmental and non-governmental organisations. All forces are brought together to improve their quality of life. Everybody contributes to this network and can be an indispensable link in this chain which only serves one purpose: to help each child, each human being, each family which is confronted with these impairments, wherever they are situated around the globe. The IF network has become the world's Spina Bifida and Hydrocephalus market place putting these impairments on everyone's agenda.

However, this success story is being affected by prenatal diagnosis which tries to detect impairments during pregnancy. When it concerns an unborn baby with Spina Bifida young parents are provided with outdated information about Spina Bifida and its prognosis. Parents are being confronted by the choice to end the life of the child they love based often on subjective negative

information. This choice, to say the least, calls for an ethical evaluation of the facts. The IF network took the lead in this ethical debate, widened the matter to all impairments and defended the right to life and treatment for all. At the same time the IF network actively promotes primary prevention with Folic Acid and advocates for mandatory food fortification because in this way the same child can be born without the impairment. With reference to the very recent debate in the Netherlands about active termination of life of newborns with Spina Bifida, a physician made a remark on the Dutch television that Spina Bifida has a bad PR. Maybe we should make Spina Bifida sexier in the same way as hurricanes which were judged in 2005 on how sexy they were to sponsors and donors.

Another threat is that in most countries the national state healthcare is going down and the privatization of health care takes over. The IF network has an important role to play to safeguard the quality of interdisciplinary care, avoiding unnecessary high tech medicine when interventions and investigations are economically profitable but do not contribute to a better quality of life. Access to healthcare for all is more and more in danger. The IF network has to maintain a difficult balance. On the one hand we have to make Spina Bifida more attractive to safeguard the right of treatment, on the other hand we have to protect the good coordinated care that was developed in recent decades. The IF network has to ensure that quality controlled knowledge is kept, developed and made available to all. With the Internet and new software this is achievable and is the new challenge for IF.

This annual report wants to make a start to work on better PR for persons with Spina Bifida and Hydrocephalus and their network. We wish to make clear who we are and what we stand for. We have been making fact sheets of all activities within the network. As a result, the 2005 annual report is not a detailed summary of activities and facts of the past year but a presentation of ourselves. A step forward towards improved Public Relations making Spina Bifida a little sexier.

Pierre Mertens

President of the International Federation for Spina Bifida and Hydrocephalus

# 2 IF, Knowledge Network of Spina Bifida and Hydrocephalus

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.

#### 2.1 IF Network

IF is a world-wide umbrella organisation of spina bifida and hydrocephalus organisations. IF aims to improve the quality of life of people with these impairments and to increase primary prevention.

IF has 27 full member organisations: Spina Bifida and/or Hydrocephalus organisations of Australia, Austria, Belgium, Denmark, Estonia, Finland, France, Germany, Guatemala, Ireland, Italy, Japan, Luxembourg, the Netherlands, Norway, Peru, Poland, Portugal, Scotland, Slovakia, Spain, Sweden, Switzerland, Turkey, United Kingdom and the United States. IF has 40 affiliated organisations worldwide with whom it has regular contact.

IF has projects running in Kenya, Malawi, Tanzania, Sudan, Uganda and Zambia. IF provides shunts and knowledge to Congo, China, Guatemala, Nigeria, Peru, Philippines, Senegal, and Vietnam. IF is a member of the European Disability Forum and PHOS (Flemish Platform for Development Cooperation). IF has the Consultative status special category with the Economic and Social Council of the United Nations and the Participatory status with the Council of Europe.

#### 2.2 IF Board

#### Mr Pierre Mertens, President

Belgian nationality. Profession: visual and contextual artist

Pierre Mertens (°1953) first child, Lies (1978), was born with spina bifida and hydrocephalus. For that reason he founded the Belgian Association for Spina Bifida and Hydrocephalus. In 1994, Mr. Mertens founded PHOS in Brussels, the Belgian Platform for Handicap and Developing Country work and stepped down as its president 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, Norwegian, and Slovak. Mr Mertens represents IF on the board of the European Disability Forum.

#### 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 this 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 Teije Dijk, Treasurer

Dutch nationality. Profession: Director of the Service for Education, Sports, Culture, Welfare, Social Care and Public Health in a municipality

His youngest son was born with spina bifida. Besides his job in a municipality, he is part-time consultant 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.

#### **Mrs Cindy Brownstein**

American nationality. Profession: CEO Spina Bifida Association and Spina Bifida Foundation

Cindy Brownstein is the Chief Executive Officer of the Spina Bifida Association (SBA) and of the Spina Bifida Foundation (SBF), a sister organisation. 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 organisation'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 organisation. These organisations represented and advocated for the 400+ voluntary hospitals in New York State.

#### Mrs Renée Höglin

Swedish nationality. Profession: 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 also published in Japan, plus hundreds of articles and leaflets on issues of disability. She has been a member of RBU (the Swedish umbrella organisation 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. 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."

#### 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 experience of working on disability issues. This includes time working for both statutory and non-statutory organisations, specializing in supporting the development of disabled people and disability organisations. Examples of this include: the development of a youth section of a national disability organisation, the setting up and project managing an IT training organisation 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 helping to get more disabled service users involved in contributing to and running their own services."

#### Mr Luis Quaresma

Portuguese nationality. Profession: director 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 it is also important 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 ( as someone with spina bifida and also as an active member of ASBIHP during the last 15 year) I can contribute to the good work that IF has being done."

#### 2.3 IF Staff

#### Mrs Els De Clercq

Belgian nationality. Developing countries project manager

Els De Clercq is a psychologist. For many years she has been actively involved in youth organisations, 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 organisation, which specialized in raising funds for projects in developing countries. During this period she became interested in helping people in developing countries. After she organized the administrative side of IF, she became project manager of the IF development cooperation projects.

#### Mr Lieven Bauwens

Belgian nationality. Overall project manager

Lieven Bauwens spent a year in lowa, 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 as board member in an exchange organisation.

#### Mrs Lorraine Leeson

Irish nationality. Consultant to IF

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 advocacy (Certificate in Feminism, Politics and the Economy, University College Dublin, WERRC).

#### Ms Marja Pia Wurzer

Dutch-Italian nationality. Intern August 2005 - May 2006

Ms Wurzer was born in Leiden (the Netherlands) on 19 July 1979. After her A-levels she spent a year in London as au pair. She was educated as a social pedagogue and during this period she did some internships abroad: in Lancaster (UK) and Siena (Italy). Afterwards she did a MA degree in Comparative European Social Studies, which is when she became interested in the work of international NGOs. Being born with hydrocephalus, Pia has a special interest for IF. With an EU Leonardo grant, she has the

opportunity to work for IF as an intern, initially focusing on the topic of mandatory food fortification and folic acid and on networking amongst NGOs. Pia has two older brothers and one younger sister and spent her childhood in Brussels. Her hobbies are spending time with friends, going to the cinema, listening to music and travelling.

#### Mr Eric Holdtgrefe

American-Dutch nationality. Volunteer

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 IF. He translated the current IF website into Spanish and Dutch.

#### 2.4 IF Consultative team

Mrs Sofie Blancquaert; legal and ethics consultant IF, lawyer

Mrs Els Blaton; technology advisor IF

Ms Olga de Wit; psychologist and consultant IF

Mr Zjuul Devens; multimedia, photography and camera work

Dr Martina Oneko; medical consultant IF, consultant paediatrics/neuro-paediatrics

Mrs Vero van den Abeele; consultant IF knowledge centre

Mrs Marjan van Mourik; management and fundraising consultant IF

Mr Geert Vanneste; consultant developing cooperation IF

Dr Carla Verpoorten; medical consultant IF, Neuro-paediatrician

Dr Benjamin C. Warf.; medical consultant IF, paediatric neurosurgeon, ABNS, ABPNS

#### 3 IF Fact Sheets

#### 3.1 Introduction to the fact sheets

IF is communicating everything it does in fact sheets. Combined they give a picture of what IF thinks is important and how it is pursuing action. IF has 4 main priorities: IF as a Knowledge Network, Prevention of Spina Bifida and Hydrocephalus, Ethics and Human Rights and the successful projects in developing countries.

4 priorities have been translated into a fact sheet each, held together by an introduction to IF.

- 3.2 IF Knowledge Network exchange of knowledge and information
- 3.3 Prevention
- 3.4 Ethics and Human Rights
- 3.5 Development Cooperation—solidarity between North and South

#### 4 IF Award

By unanimous decision of the International Board, it was decided that the IF Award for the year 2005 would be given to Dr Ben Warf for his work in thrusting back the frontiers of knowledge for the treatment of Hydrocephalus in Africa.

10 years ago, IF started a pilot project for early intervention, treatment, rehabilitation and follow-up of children with Spina Bifida and Hydrocephalus in Africa. Dr Warf has been a partner in the project from the beginning and became the IF Medical Consultant on neurosurgery. The aims of this IF project in Africa are to prevent Spina Bifida and Hydrocephalus as much as possible, and improve the lives of persons with these impairments and their families, by organising appropriate training, surgery and rehabilitation, through existing medical, therapeutic and community based services in the different partner countries.

In 2005, the Journal for Neurosurgery, Paediatrics published four articles written by Dr Warf. One was regarding the results using ETV as the method of treatment for children with Hydrocephalus. The second article compared the expensive Codman shunt with the much less expensive Indian Chhabra shunt. A third combined two techniques to improve the outcome of the surgery. As Medical Director and Chief of Surgery at the CURE Children's Hospital of Uganda he developed an achievable neurosurgical programme for the treatment of Spina Bifida and Hydrocephalus. Dr Warf knows how to translate the latest technology into a useable system for Africa. He is also very involved in transferring this knowledge to local physicians. This has resulted in the Cure PATH Programme. This is a training programme which transfers the results obtained in Uganda to other countries and regions. With his dedication to treat children with Spina Bifida and Hydrocephalus in Africa, Dr Warf is crossing borders all the time thereby influencing medical practice worldwide.

The International Federation for Spina Bifida and Hydrocephalus motivated its decision by saying that the driving force of Dr Warf is to fight for the poorest of the poor, like the disabled people in Africa, for those that may otherwise be denied the benefit of health services. The high quality of service in his hospital resulted in important advances in the treatment of hydrocephalus in Africa and world wide.

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) and Ryggmargsbrokk- og Hydrocephalusforeningen, the Norwegian association for Spina Bifida and Hydrocephalus.

# 5 Financial Report

### 5.1 Report of the auditor

This is the report of the statutory auditor on the financial statements for the fiscal year ended 31 December 2005 - 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 31-12-2005, prepared under the responsibility of the board of directors of the federation, which show a balance sheet total of  $\le$  367.961,98 and a loss for the year of  $\le$  9.434,24.

Our audit of the financial statements was carried out in accordance with the auditing standards, as issued by the Institute of Company Auditors [Institut der bedrijfsrevisoren / Institut des Reviseurs d'Entreprises].

#### UNOUALIFIED AUDIT OPINION ON THE FINANCIAL STATEMENTS

The above mentioned auditing standards require that we plan and perform our audit to obtain reasonable assurance about whether the financial statements are free of material misstatement.

In accordance with those standards, we have taken into account the administrative and accounting organisation of the federation. 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 31/12/2005 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 21th 2006 - BVBA De Nul & co bedrijfsrevisor - Statutory auditor represented by Roger De Nul

# 5.2 Balance Sheet 31 December 2005

Assets	31-dec-05	Liabilities	31-dec-05
TANGIBLE ASSETS	3.461,64 €	RESERVES	324.513,53 €
Investments Depreciations investments	8.097,00 € -5.131,15 €	Subscripted capital Profit-losses reported Profit-los bookyear	82.994,30 € 250.953,47 € -9.434,24 €
Rent caution	495,79 €	Trone to bookyea.	7. 13 1,2 1 0
AMOUNTS RECEIVABLE	8.841,31 €	AMOUNTS PAYABLE	39.236,75 €
Custumors Advances projects Advances other	3.376,58 € 3.923,49 € 1.541,24 €	Suppliers Invoices to recieve Salary's to be paid Provision holiday fee	28.337,52 € 0,00 € 0,00 € 10.899,23 €
BANK & CASH ACCOUNTS	355.304,25 €	ŕ	•
Stocks KBC - accounts KBC - accounts saving Cash accounts Internal transfers	104.151,79 € 144.101,05 € 106.992,82 € 58,59 € 0,00 €		
TRANSIT ACCOUNTS	354,78 €	TRANSIT ACCOUNTS	4.211,70 €
Costs for next year	354,78 €	Profits for next year	4.211,70 €
Total assets	367.961,98 €	Total liabilities	367.961,98 €

# 5.3 Profit and Loss account 2005

	Costs	381.338,04 €
Diverse costs		280.960,59 €
Office		5.624,28 €
Office supplies		10.144,20 €
Publications - copy		171,23 €
Documentation - books		379,93 €
Public relations - fundraising		1.357,21 €
Communication		4.085,75 €
Transporters		2.629,87 €
Membership fees		825,00 €
External expertise		19.370,79 €
Insurance		744,41 €
Transport expenses		22.680,90 €
Official documents (visas)		497,74 €
Representation		3.906,33 €
Medical material projects		68.713,03 €
Salary's in projects		38.106,07 €
Training projects		29.409,66 €
Other expenses projects		44.218,19 €
Conferences - meetings		28.096,00 €
Salary		84.192,91 €
Gross salary		57.974,65 €
Extra-legal benefits		6.573,68 €
Social charges		13.560,08 €
Provision holiday fee		5.898,94 €
Insurance personnel		185,56 €
Depreciations		2.698,73 €
Diverse taxes		500,00 €
Financial costs		3.891,31 €
Bank charges		3.614,83 €
Exchange differences		276,48 €
Exceptional costs		9.094,50 €
	Result	-9.434,24 €
	Costs	381.338,04€

371.903,80 €	Income
354.228,73 €	General income
3.000,00 €	Membership fees
210,00 €	Membership fees individuals
264.388,59 €	Subsidies project Norad
52.542,13 €	Subsidies project SHIA
5.752,56 €	Subsidies project Ethics (EU)
750,00 €	Subsidies project other
5.918,52 €	Donations - fundraising
4.065,00 €	Donations - General (KBS)
17.601,93 €	Diverse recuperation (
8.067,84 €	Financial income
7.577,23 €	Financial products
490,61 €	Exchange differences
9.607,23 €	Exeptional income
371.903.80 €	Income

# 5.4 Staff according the social balance

Amount of days worked	405 days
Amount of hours worked	3.078,00 hours
Bank holidays	13 days
Holidays	25 days
Illness	1 day
Legal absence	1 day
Staff employed	2
Average full time equivalent	1,8 FTE

# 6 Acknowledgements (i.e. projects, donors and volunteers)

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, i.e. **the Netherlands, Norway, Portugal, Sweden, United Kingdom and United States**.

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.

All NGO's and its devoted staff in the IF projects in developing countries.

The EU and Oever, a cooperative of congregations in Flanders, supported the Ethical project in new Accessed EU countries, which was finalized in 2005.

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, via the King Baudouin foundation or not, contributed to our work and projects, which would not be possible without them.

And last but not least, IF wishes to thank its many volunteers and friends, without whom this work would not have been possible:

Ala-Rantala Anu at SHIA Baroch Tom 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 the Election Committee and language

control

De Greveleer Patrick from the Dentsu BLD group

De Schutter Anna for data management

Devlieger Patrick for advice on research projects

De Wit Olga for action on ethics and human rights

Eskes Tom for advice on prevention

Gillis Philppe for medical advice and training in the South Hjelt Kerstin for the Friends of IF and logistic support on congresses

Hjelt Bo management and advice on fundraising

Holdtgrefe Eric for translation

Leyssens Werner for legal advice

Maitreau Antoine and Catherine for language control

Melis Ann translation video's

Mertens Marianne for translation French

Mertens Leen and Raes Tom for the Liesje Mertens Fonds

Mertens Charles for advice staff administration

Putseys Tom for advice on software and development of the website

Raeymaeckers Mol, language advice

RBU and especially the Spina Bifida and Hydrocephalus group with Karin Berggren, Höglin Renée, Toft Eva and Rundström Björn for commitment to the work on development

cooperation and the contact with SHIA

Rochtus Marc for technical assistance with the videos Ryggmargsbrokk- og Hydrocephalusforeningen, especially Løvik Njål, Schoyen Runa, Skattebu Eli and Spiten Ann Eli for commitment to the work on development cooperation and the contact with Atlas

Sarsfield-Keily Phillippa Friends of IF and language control Schoven Runa Election Committee

Struyf Marc for advice on graphics

Van den Abeele Vero for the development of the IF

Knowledge Centre

Van Mourik Marjan for management and fundraising advice Verpoorten Carla for medical advice and training in the South

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.

# IF ivzw

# International Federation For Spina Bifida and Hydrocephalus Consultative status special category with the Economic Council of the United Nations / Participatory status Council of Europe

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