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Manana Enkya Kesho aupro



INTERNATIONAL
FEDERATION
for
SPINA BIFIDA
and
HYDROCEPHALUS

“Tomorrow”

Annual Report 2007

IF ivzw

International Federation for Spina Bifida & Hydrocephalus

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

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

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Annual report 2007: Introduction

The conference of the International Federation for Spina Bifida and Hydrocephalus (IF) in May 2007, “Tomorrow”, was held in Kampala (Uganda) and focused on prevention. Primary prevention is one of the three priorities of the current board, as are the IF Knowledge Network on Spina Bifida and Hydrocephalus and the financial sustainability of IF.

Primary prevention took a major part of our work in 2007 and therefore, it is the focus of this annual report. By hosting a high-level working meeting for the Flour Fortification Initiative (FFI) November 2007 in Brussels, IF made a major contribution in the fight for flour fortification in Europe. FFI got the IF award 2007 for its efforts in fortification of staple food with Folic Acid worldwide. Primary prevention is the most human solution in the prevention of Neural Tube Defects.

2007 was also the year of the Convention on the Rights of Persons with Disabilities, adopted by the United Nations General Assembly in December 2006 and opened for signatures in March 2007. Through the European Disability Forum (EDF), IF contributed to the content of this important human rights tool by emphasizing disability in all development cooperation actions and including the right to access to treatment for all persons with a disability if this treatment is improving the quality of life. IF and its members fully support this convention and will stimulate the ratification in all countries where IF is active. The convention is an additional tool in the ethical debate on termination of life in newborns in which IF has taken the lead.

The North - South solidarity projects expanded and benefited from an enlarged interest in our results and several new requests for support in more developing countries. IF is confident to gain interest of more members in the North to start projects in the South. UK and Belgium have already shown enthusiasm and an entrepreneurial spirit, working towards results in 2008. Italy, Denmark and others are investigating opportunities for North - South solidarity. In 2007 we finalized the internet-based information database of our network and we will launch the trial version at the 2008 conference in Lisbon.

2007 was definitely the year where we laid the foundation of a more stable income for the own organization, due to the cooperation with the European Commission and the Flour Fortification Initiative. We are conscious that this builds upon the work of many years mainly done by many volunteers, and we are glad that we will be able to support the work of our volunteers in a more professional way.

I want to thank all volunteers of the IF network, partners in the South and the North, my board and staff for their valuable input towards these positive results and developments.

You will find more about all this in this annual report and I hope you will enjoy reading it.

Pierre Mertens
IF President

The International Federation for Spina Bifida and Hydrocephalus

Board of Directors

Mr. Pierre Mertens, president, Belgium
Mrs. Eli Skattebu, vice-president, Norway
Mr. Teije Dijk, treasurer, The Netherlands
Mrs. Cindy Brownstein, member, USA
Mr. Jon Burke, member, UK
Mrs. Renée Höglin, member, Sweden
Mr. Luis Quaresma, member, Portugal
Mrs. Victoria Sandoval, member, Guatemala
Mrs. Maria Cristina Dieci, member, Italy



The board met in person in January, May and December 2007.

Pictured L-R: Mr. Luis Quaresma, Mrs. Eli Skattebu, Mrs. Renée Höglin, Mr. Jon Burke, Mr. Pierre Mertens, Mrs. Victoria Sandoval, Mr. Teije Dijk. Not pictured : Mrs. Cindy Brownstein and Mrs. Maria Cristina Dieci.

Brussels office:

Mr. Lieven Bauwens, General Coordinator
Mrs. Els De Clercq, Coordinator Development Cooperation
Ms Pia Wurzer, replaced in April 2008 by Ms Hilde De Keyser, Policy Officer Prevention

Kampala Office:

Mrs. Rebecca Nakitto Sagabo, Administrative Coordinator – East-Africa.
Mrs. Olivia Nakato, Policy Officer Human Rights

Representation

The International Federation for Spina Bifida and Hydrocephalus holds the Special Consultative Status at the Economic and Social Council of the United Nations (renewed in 2007) and the Participatory Status at the Council of Europe.

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

The president holds board memberships of the European Disability Forum (EDF), Bo Hjelt foundation, Flemish Spina Bifida and Hydrocephalus Association and is a member of the General Assembly of CBM Belgium. In 2007, the president's book "Liesje" was published in Italian.

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

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

In 2007, board members actively participated in the representation of IF by attending several conferences, among others, the European Commission's seminar "Active Players in the Internal Market" and EDF's General Assembly.

IF Consultative Team

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



Prevention of Spina Bifida and Hydrocephalus

" Why should we prevent who we love ? "

By Pierre Mertens, President IF, Brussels

It is a discussion I often had with my wife Mol. If Folic Acid could have prevented the Neural Tube Defect of our daughter Liesje, she probably would still be here. She could be a 30 year-old young lady, married with children. She would not have had the 10 shunt revisions, the incontinence, and the mobility problems. Mol responded to it: " Liesje was Liesje, also because of her disability. It is the way she was and the way we loved her. She would not have been the same person without her disabilities."

Liesje was special, indeed also in the way she coped with her problems; how she was able to comfort us when we were anxious or depressed; how she brought people together. She functioned as a catalyst. Why should we prevent who we love?

Today, with ETV, a new technique in treating Hydrocephalus, all these shunt problems would not occur anymore and she could also become as many others with Spina bifida a 30 year old lady, married and with children.

Anyway, preventing what already occurred is impossible. Prevention always relates to the future, to tomorrow.

Prevention measures for the next generation should not bear a judgment about the value of the life of any person with Spina Bifida and Hydrocephalus. On the contrary, persons with Spina Bifida and Hydrocephalus play an important role in the contemporary society where everybody is competing to have an ideal weight, color and career. Disabled persons are questioning the common lie that all pain and suffering can be solved or prevented.

Society can learn from the daily fight of persons with Spina Bifida and from the love of their caregivers, mothers, fathers, siblings and devoted professionals. We can learn from how inventive they are in overcoming problems and how they show real solidarity between the North and the South like the Scandinavian countries show in Africa. The international IF solidarity is an example for all disability specific organizations worldwide.

So, there is nothing wrong with us! Quite the opposite is true. Why should we prevent such wonderful people?

Well, the associations for Spina Bifida in many countries themselves took the lead for prevention, defending the value of lives of persons with Spina Bifida and Hydrocephalus by questioning secondary prevention. Because the wonderful thing on primary prevention is that nobody is killed because of their disability. All prevention initiatives have to go hand in hand with good care of all persons with the condition and further fundamental research of the



real causes of Spina Bifida and Hydrocephalus. It's an established fact that a daily intake of 0.4 mg of Folic Acid, at least two months prior to the conception and the first months of pregnancy, reduces the incidence considerably. In the words of our Australian association "if a woman stops taking the contraceptive pill she has to switch to another pill, called Folic Acid".

Folic Acid is a vitamin B that is needed to be in top condition. I take it too; it is good for all of us.

But informing and influencing the general population is very difficult. Therefore, IF is advocating for mandatory fortification of staple food with Folic Acid. UK's ASBAH took the initiative for an IF resolution in this matter and the Flour Fortification Initiative was and is a great partner in making progress in governments taking vital decisions.

Taking Folic Acid helps, but there is more. There is a deficit of Folic Acid in the mother's blood. But why is there this deficit? This needs further research: a study in Flanders revealed that the incidence of Spina Bifida is higher in areas where there are incinerators with dioxin emissions. Dioxin is presumed to disturb the properties of Folic Acid. In some parts of Africa cooking is done inside on open wood fires, without a chimney. People there use waste wood which might contain toxic chemicals like dioxin. In some parts of South Africa and Guatemala there is a Spina Bifida incidence of 1 out of 150 live births instead of the average of 1 out of 1000. The causes are thought to be related to moldy corn products. The mould presumably releases a toxin which disturbs the effects of Folic Acid. A veterinarian once told me that, after a wet summer, the Spina Bifida incidence in pigs increases significantly. Some antibiotics even counter the effect of Folic Acid. If these products are used in cattle-feed they inevitably end up in our food.

Further research on the real causes of Spina Bifida is needed because an extra daily dose of Folic Acid can hide the real cause of this low level of Folic Acid in the mother.

While at present, unborn children with impairments in the North are being systematically eliminated after a prenatal diagnosis, they not only kill a valuable human life, but also eliminate the symptoms of a cause that will remain unknown. They will stop looking for the cause because the problem is no longer visible.

As a result, Spina Bifida threatens to be an impairment of the South where prenatal diagnosis is hardly developed. We know that, for illnesses like malaria which mainly occur in the South, there are far fewer means for treatment and scientific investigation. As a result, together with Spina Bifida in the North, research grants for further investigation are being eliminated too and these causes are likely to create other illnesses.

In developing countries we see a very high Hydrocephalus incidence. Within the IF network, Dr. Benjamin Warf, an American pediatric neurosurgeon, has been working for years in Uganda. He developed several investigations that now, even in the North, contribute to a better knowledge and treatment of Hydrocephalus. So, we found that in Uganda a major cause is the poor



treatment of postnatal meningitis.

Probably the bad hygienic circumstances and habits during delivery cause so many infections. In case of fever, the traditional healers often think it is malaria and before mother and child reach a qualified physician, the infection has already deteriorated into meningitis. Infections and inadequate treatment are probably the main causes of hydrocephalus in developing countries. IF attempts to treat these children but is also stimulating further investigation into the causes which, of course, are more far-reaching and affect far more people than only this mother and her child.

Prevention is better than cure. On the other hand, prenatal diagnosis is wrongly described as prevention. It's obvious that nothing is prevented. It's early detection, with the aim of eliminating unborn children with impairments. Therefore the IF network discussed and reached two other resolutions. One resolution against elimination of disabled unborn children after prenatal screening and another resolution against active termination of life of newborns with Spina Bifida were reached by IF.

Every illness or impairment has a cause that might have been prevented and therefore it should be a point of attention at every step in medical care.

Preventative measures for pressure sores for example are much easier than the treatments, which sometimes demand complex plastic surgery. Paralyzed people need to change their sitting-position regularly, they need a good seat-cushion, braces and shoes must not pinch and the skin has to be checked regularly for red spots.

All children with Spina Bifida are born with a paralyzed, but intact bladder and normal kidneys. Nevertheless, the majority of those children seem to have serious bladder and kidney damage, by the age of one. In this field the healthcare system didn't succeed in preserving the originally intact bladder and kidneys.

With the right preventative strategy, most of the children with Spina Bifida are dry, infection-free and don't show kidney or bladder damage. The fact of being dry already is prevention against social exclusion. If you smell like urine or stool, you are being shut out. If the person is dry, he risks far less pressure sores, skin- and bottom-problems. Also overprotective education of a child with a disability leads to problems to become an independent adult. Preventive education supports and empowers the child to reach their goals.

In a certain way, every action should contain prevention. Coming back at my question; should we prevent who we love? No, we have to take care of those we love and by taking care we see their valuable lives, but we also see their problems. If we can prevent these problems in newborns, we should do it. When Liesje died I did not miss her wheelchair. I missed Lies, her smile, her heart, her love.

It is because we love, we prevent. ■



"The Silent Conspiracy"

By Asook C. Antony, MD, FACP

Professor of Medicine, Department of Medicine, Indiana University School of Medicine, and the Richard L. Roudebush Veterans Affairs Medical Center, Indianapolis, Indiana, USA

What are the formative influences in our career path that lead us to advocate for a specific group of patients? The intellectual challenge of their disease? An experience with a patient or family member? A gifted teacher? Yes, any of the above!

But perhaps overriding all these is an invitation that coincides with our highest ideals, a promise of fulfilling a romantic void deep within one that touches and heightens our senses, our sensitivities, and restores balance to our lives. And then, there is the lure of patients themselves cheerleaders involved in a silent conspiracy.

For me, this call began with drama bathed in tragedy. It was mid-summer 1972 in Ludhiana within the Indian side of the vast Punjab and the air was thick with a sickening blend of phenol and the sweat of labour. The exhausted mother had just let out a primeval scream as we witnessed and collectively experienced the unspeakable horror which accompanies the unexpected birth of a baby with Anencephaly. That near normal face with no brain is a haunting image... even today. But this baby was breathing, so they swaddled and laid her in a bassinet by the far side of the delivery room until she departed silently... without fanfare or tearful goodbyes. Little did I realize then how much this baby would affect my career choices.

Just over 5 years ago, armed with a Fulbright scholarship, I travelled to my alma mater to ask a simple question: "What's going on with prevention of Neural Tube Defects (NTDs) [Anencephaly and Spina Bifida] in India?" That adventure led to the shocking discovery that the incidence of NTDs in vast areas throughout North India was among the highest in the world! Not unexpectedly, the Spina Bifida Association of India wanted me to relate this story at their inaugural meeting in Mumbai. But I should have known better—the conspiracy of the silent witnesses was at work. This high-powered scientific conference was rife with unforgettable memories and images for those who peered even deeper....

On entering the auditorium we were politely greeted by dozens of children with Spina Bifida who sat among us evoking indulgent smiles, warmth, and strengthening bonds—each embraced as a hero. How very correct! "Today is our special day," one of them looked up at me beaming, as we posed for pictures, holding fingers in 'V for Victory' signs. "We even got Chhutti (holiday) from school!" At the opening ceremony, a dozen such children with varying grades of paresis gamely helped one another up the stage in a silent rendition of "He ain't heavy, he's my brother!" Their invocation hymn (as dignitaries lit the traditional oil lamp) was from the internationally-acclaimed 1950s Indian film ["Do Anken, Barah Haath" "Two Eyes, Twelve Hands"] which was about successful reformation of hopeless criminals...against all odds. But was I the only one who saw deeper connections between "the-hopeless-as-yet-not-born-with-NTD" and the hope of NTD-prevention? And did I just hear 12 innocents with folded hands implore us to keep them in our prayers?



There was this handsome Muslim couple who brought their baby with meningomyelocele for an ultrasonography demonstration; that child's mother taught us something about the dignity and solidarity of motherhood. Just before placing her baby on the pedestal, she straightened herself, threw back her veil, and with slow deliberation scanned the audience proudly with a half-smile. Then she whispered "Assalamualaikum" ("Peace be with you") as she bowed her head and raised her right palm to her forehead. But was I the only one who heard her wordlessly say: "Look at me... my baby is as beautiful as me!" Indeed she was grace personified... "Walaikumsalam" ("Peace be with you too"). Yes, my sister may all good things come to you!

Every speaker had a unique story or encouraging message to share. This European artist, president of an international organization dedicated to NTDs, was father of "...a wonderful and intelligent daughter who fully enjoyed her life. Who loved music, art, had many friends, went to an ordinary school... ..and fell in love every second day! She had Spina Bifida and died when she was eleven, after shunt revision...."

The Belgian physician-advocate against euthanasia, a mother from the Dutch NTD Support Group, the Australian physiotherapist, a champion for global folate food-fortification from the CDC, and a heterogeneous congregation of academic pediatric surgeons, urologists, orthopaedicians, and neurosurgeons from the UK, USA, and India they just could not help being there! So the conference organizers once lone voices in the wilderness crying for change were now among family! More warmth!

The American pediatric neurosurgeon who operated on over 3000 Ugandan children for Hydrocephalus and Spina Bifida had more to tell us about his call so much greater than how he had tamed the ravages of Hydrocephalus using an indigenous catheter and a pioneering technique. These were indeed cause for celebration and that we did, collectively!

But there was still cause for concern: A peripartetic obstetrics nurse from Kansas flitting between 19 mission hospitals in India observed a troubling all-pervasive apathy towards advising women about the ease of primary and secondary NTD-prevention with folate supplements. The consequence? Soon after a lecture on NTD and its prevention for 500 factory workers in Punjab, a woman came forward weeping uncontrollably she had delivered six consecutive babies, each with Anencephaly, and just realized with horror during the lecture that she had still not been given the right advice before her seventh pregnancy! An Indian social worker mesmerized us with graphic pictures and described in painful detail the innumerable problems faced by children with Spina Bifida in villages. She was a captive and would surely snare many more to "the cause" with such lectures, I thought! In the end, she blurted out: "I'm going for a PhD for them...!"

Finally, there were the courageous mothers of children with Spina Bifida. Brave Hearts, Pillars of Strength for one another, each an embodiment of grace under pressure, carrying a burden greater than anyone else. Each conference participant was heeding a personal call, and experienced what Wordsworth beautifully wrote in Lines composed a few miles above Tintern Abbey:



*" And I have felt
A presence that disturbs me with the joy
Of elevated thoughts; a sense sublime
Of something far more deeply interfused..."*

That "presence" that "rolls through all things", together with innumerable "little helpers" have targeted us all in a silent conspiracy to maintain focus on their behalf.

Now three decades later with the clarity of hindsight it all makes sense. But at each cross-road, how did I manage to ask the relevant questions how does folate enter cells, cross the placenta, and then enter the developing foetal brain? Was I not led...? "From origins in fundamental research to now hoping to effect policy changes that dramatically improves the nutrition of millions of women in India...?!" students and peers ask rather incredulously, "Isn't this well beyond your training?" And a little voice inside challenges: "You're not afraid or intimidated no fear of failure?" Hardly! Just after I outlined challenges for India (about food-fortification with folate and vitamin B12), this Hindu mother carrying a paralyzed child on her hip instinctively reached up and tenderly stroked my face in an expression of love. Then she said: "If Paramatma (God) wants you to succeed, no one can stop you!" I seriously doubt she read any of St. Paul's letters. But her quiet confidence felt like ... a benediction!

So what does moving far out of our comfort zones and immersion in such enterprises getting wet, in the thick of the battle do to us? I speak only through nascent experience: Yes, there are moments of "numinous consciousness". And with each prompt, we perceive seed events in guidance, until all work appears permeated with this sense of reverence. Then work itself [happily] becomes the applied edge of our deepest beliefs and we are being gradually transformed into our highest ideals.

Finally, no event or effort is entirely wasted...

Twenty-eight years following that delivery room experience, I saw a baby with meningomyelocele curled up in a formalin jar in an anatomy museum. What a waste, I thought initially. But was it really...? Not long ago, when I held one of these babies in my hands, it was yet another surreal moment: Here we were, surrounded by 25 babies with NTD just lifted out of a formalin container looking for 'the most photogenic babies'! Those heart-rending photographs have now been shown to thousands of women in India [they are even in a best-selling hematology textbook] with a victorious message: 'Yes, NTD-prevention is possible!' So did those babies make a difference to even one prospective mother?

What's next on the agenda you ask? With recognition of a significant problem in India comes the challenge to try to change the status quo especially for 200,000 "very-special-little-persons" each year. A deafening call from the unborn to me!

While preparing for another week's experience with jet lag, I discussed these plans with a friend and colleague. Tom, a past-president of the American Society of Pediatric Neurosurgeons, was tired from having operated all day, but listened intently. Then he put down his glasses, looked through my eyes, and softly said with conviction: "From my perspective, if you can prevent even one baby from getting NTD, your entire trip would be more than worth the effort"!



“Folic Acid Fortification”

By Sir R. Bayston, Andrew Russell, N. J. Wald and A. V. Hoffbrand

Association for Spina Bifida and Hydrocephalus, 42 Park Road, Peterborough PE1 2UQ, UK; Wolfson Institute of Preventive Medicine, London, UK (NJW); and Royal Free Hospital, London, UK

Mr. Andrew Russell has for long been a strong advocate for fortification with Folic Acid. For years, the Association for Spina Bifida and Hydrocephalus had to fight to overcome (scientific) prejudices. Especially in 2007. Among others, Mr. Russell formulated an answer to the perceived cancer risk of Folic Acid Fortification.

After long deliberation, the UK Food Standards Agency (FSA) has recommended the fortification of flour with folic acid to reduce the numbers of pregnancies affected by neural tube defects. However, on Oct. 17, 2007, the FSA indicated that a decision on fortification is to be delayed until the Chief Medical Officer considers recent publications on the issue of folic acid and colorectal cancer. Two papers are likely to be considered: Cole and colleagues¹ and Mason and colleagues².

The Cole paper reports the results of a randomized trial of folic acid in prevention of colonic adenoma recurrence in a group of patients who had had adenomas removed. The conclusions have been misinterpreted. The paper does not show that folic acid supplementation poses a hazard. It relates to colorectal adenomas (benign tumors), not carcinomas. The incidence of adenomas in those who were and were not allocated folic acid supplements was almost identical over the two 3–4 year consecutive periods of follow-up (relative risks of 1.04 [p=0.58] and 1.13 [p=0.23]).

Cole and colleagues correctly conclude that 1 mg/day folic acid did not reduce colorectal adenoma risk, but neither did it increase it. The results (table 3 of the paper) are negative. The only hint of increased adenoma risk is in a subset analysis related to the incidence of three or more adenomas. Secondary analyses, when based on such small numbers (13 placebo, 30 folic acid), are prone to the effects of chance producing formally significant results, particularly when there was no excess risk (relative risk 0.97) in people with one or two adenomas. A similar trial showed no excess of adenomas with folic acid³.

The paper by Mason and colleagues reports on a temporal association between folic acid fortification and an increase in colorectal cancer in the USA and Canada. Mason and colleagues suggest the possibility of a causal link, but the data do not support this. The incidence of colorectal cancer declined until 1995 in the USA and 1996 in Canada, then increased. Mandatory folic acid fortification was in place by January 1, 1998, in the USA and about a year later in Canada. The rise in colorectal cancer incidence therefore started before the introduction of fortification on any large scale and so could not have been caused by fortification. Figure 3 in the paper shows that endoscopy rates for colorectal cancer among people aged 50 years and older increased after 1996. Cancer screen-

1. Cole BF, Baron JA, Sandler RS, et al, for the Polyp Prevention Study Group. Folic acid for the prevention of colorectal adenomas: a randomized clinical trial. *JAMA* 2007; 297: 2351–59.

2. Mason JB, Dickstein A, Jacques PF, et al. A temporal association between folic acid fortification and an increase in colorectal cancer rates may be illuminating important biological principles: a hypothesis. *Cancer Epidemiol Biomarkers Prev* 2007; 16: 1325–29.

3 Logan RFA, Grainge MJ, Shepherd VC, Armitage NC, Muir KR. Aspirin and folic acid for the prevention of recurrent colorectal adenomas. *Gastroenterology* 2007; published online Oct 11. DOI: 10.1053/j.gastro.2007.10.014

4. US Cancer Statistics Working Group. United States cancer statistics: 2003 incidence and mortality. Atlanta: Centers for Disease Control and Prevention and National Cancer Institute, 2006.

5. Canadian Cancer Society/National Cancer Institute of Canada. Canadian cancer statistics 2007. Toronto: Canadian Cancer Society/National Cancer Institute of Canada, 2007.



ing is always associated with an increase in incidence because of the effect of early detection. Colorectal cancer mortality rates in the USA show no upward trend. The rates decline by about 2% per year between 1990 and 2000⁴. Canada also had a continuing decline in colorectal cancer mortality rates from 1978 to 2003⁵. The paper by Mason and colleagues therefore provides no grounds for concern. It is misleading to link the rise in incidence between 1996 and 2000 to folic acid fortification.

The FSA and the Chief Medical Officer can be confident in recommending that the UK Government introduce the mandatory fortification of flour, which could prevent about 400 pregnancies affected by neural tube defects each year, reducing both the number of terminations of pregnancy and of children born with these defects.

We declare that we have no conflict of interest.

Reprinted from The Lancet, Vol: 370; Bayston R, Russell Andrew, Wald NJ, Hoffbrand AV; "Folic Acid Fortification and Cancer Risk"; 2004; Copyright: 2007, with permission from Elsevier.



“The risk of fumonisins”

By Prof. Dr. Wentzel Gelderblom

Director PROMEC Unit, South-African Medical Research Council

Studies related to the possible role of fumonisins in the development of Neural Tube Defects (NTDs) have been reviewed suggesting the impairment of folate uptake as a possible mechanism⁶. Studies implying a possible link between the fumonisins and the incidence of NTD in countries such as China, South Africa and the Texas-Mexico border were highlighted. A recent study showed that the consumption of tortillas during the first trimester in a population along the Texas-Mexico border was associated with an increased odds ratio (OR) to develop neural tube defects⁷. This association was based on the postpartum Sa/So ratio in that increasing levels of fumonisins exposure were associated with increasing ORs for the incidence of NTD.

Estimated fumonisin exposure in Guatemala due to the consumption of nixtamalised maize products in the form of tortillas is likely to exceed the recommended provisional maximal tolerable daily intake of 2ug/kg bw/day set by the WHO⁸. When considering the urinary level of FB1 in a Mexican woman cohort more than half of the study population had detectable levels, which was associated with maize-based tortilla consumption⁹.

As tortilla preparation reduced the level of the fumonisins intake the latter should be much higher if maize is consumed directly via other means especially in the African context.

6. Marasas, W.F.O., Riley, R. L., Hendricks, K. A., Stevens, V. L., Sadler, T. W., Gelineau-van Waes, J., Missmer, S. A., Valverde, J. C., Torres, O. L., Gelderblom, W.C.A., Allegood, J., de Figueroa, A. C. M., Maddox, J., Miller, J.D., Starr, L., Sullards, M.C., Trigo, A.V.R., Voss, K. A., Wang, E. and Merrill, A.H. Jr. (2004). Fumonisins disrupt sphingolipid metabolism, folate transport and development of neural crest cells in embryo culture and in vivo: A potential risk factor for human neural tube defects among populations consuming fumonisin-contaminated maize. *J. Nutr.*, 134, 711-716

7. Missmer, S.A., Suarez, L., Felkner, M., Wang, E., Merrill, A.H. Jr. and Rothman, K.J., Hendricks KA. (2006) Exposure to fumonisins and the occurrence of neural tube defects along the Texas-Mexico border. *Environ. Health Perspect.* 114, 237-241.

8. Torres, O.A., Palencia, E., Lopez, de P. L., Grajeda, R., Fuentes, M., Speer, M.C., Merrill, A.H. Jr, O'Donnell, K., Bacon, C.W., Glenn, A.E. and others. Estimated fumonisin exposure in Guatemala is greatest in consumers of lowland maize. *J. Nutr.* 137, 2723-2729.

9. Gong, Y.Y., Torres-Sanchez, L., Lopez-Carrillo, L., Peng, J.H., Sutcliffe, A.E., White, K.L., Humpf, H.U., Turner, P.C. and Wild, C.P. (2008) Association between tortilla consumption and human urinary fumonisins B1 levels in a Mexican population. *Cancer Epidemiol. Biomarker Prev.* 17, 688-694.

“Prevention of secondary disabilities: CIC and Bowel Management”

By Mr. Lieven Bauwens,
IF General Coordinator

Dr. Carla Verpoorten and Mrs. Maria-Helena Christiaens have been active in training staff in IF projects in developing countries. All too often children with Spina Bifida are facing secondary disabilities that could have been prevented by the proper management of the problems they have. Clean Intermittent Catheterization has proven to be a cost-effective and sustainable solution for urinary incontinence of children with Spina Bifida. When these children are able to control their bladder and bowel through an efficient continence management programme, they can get schooling preventing social exclusion.

Dr. Carla Verpoorten has decades of experience with children with Spina Bifida, both at the University Hospital of Leuven as in developing countries. She concludes¹⁰:

Medical management with CIC and anticholinergics is effective in preserving renal function and providing safe urinary continence in more than 90% of patients with a neurogenic bladder. Early diagnosis and treatment institution, long before continence becomes an issue at toddler age, can prevent both renal damage and secondary bladderwall changes, thereby improving long-term outcomes. Compared with oral oxybutynin, intravesical oxybutynin has more potent and longer-acting detrusor suppressive effects with good tolerance and should be used prior to considering surgical therapies. Therapeutic goals should no longer be restricted to prevention of secondary damage to both upper and lower urinary tracts. Instead, our goal should be to achieve normal renal and bladder growth at safe bladder pressure, with appliance-free continence.

Dr. Verpoorten and Mrs. Christiaens have also successfully implemented a bowel management programme using as many local means as possible. Cost effective and a simple way to get children with Spina Bifida dry and clean, a key to including them in society

10. Verpoorten C, Buyse GM., The neurogenic bladder: medical treatment., *Pediatr Nephrol.* 2008 May;23(5):717-25.

Prevention: IF Award 2007

Hon. Mrs. Janet Museveni hands over the IF Award to Prof. Dr. Glen Maberly



The 2007 IF award was handed over to Prof. Dr. Glen Maberly, coordinator of the Flour Fortification Initiative (FFI), during the conference of the International Federation for Spina Bifida and Hydrocephalus in Kampala, Uganda in May 2007 by Mrs. Janet Museveni, First Lady of Uganda and a member of the Ugandan Parliament.

Each year, IF presents the IF Award to an individual or organization in recognition of the special contribution they have made to the service of people with disabilities in general or to people with Hydrocephalus and Spina Bifida in particular. The award itself is in the form of a bronze statue, representing an Etruscan woman with a hole in her back and abdomen. It is representing both ‘the pregnancy in danger by prenatal diagnoses’ as the ‘disability’. The view through the body represents hope. It is a focused way of perceiving the world through the hole in the back of people.

FFI is a network of individuals and organizations working together to make micronutrient fortification of flour produced by large roller mills standard practice. The network is composed of representatives of private, public and civic organizations who combine their resources and collaborate to foster flour fortification. The representatives are farmers, wheat procurement and marketing organizations, millers, mill manufacturers, producers and/or distributors of flour improvers and fortificants, food industries that use flour, non-government organizations, agencies of the United Nations, government agencies and other national entities.

FFI was awarded considering the theme of the 2007 conference “Tomorrow – prevention of Spina Bifida and Hydrocephalus & prevention of secondary handicaps,” considering the progress FFI made in Australia, Asia and some African and European countries, considering their scientific persistence in preventing Neural Tube Defects and not in the least, considering the excellent working relationship IF has with FFI.

The mission of FFI is to stimulate interaction and partnership between the public and civic sectors and the grain and flour industries to inform and encourage these industries to make fortification of flour a normal part of large roller mill flour production.

Fortification of a staple food is a highly effective tool to improve public health. The success of the salt iodization efforts demonstrates what can be achieved when a product-specific industry assumes leadership in improving public health. Wheat flour fortification offers a tremendous opportunity to improve the vitamin and mineral status of populations because more than 400 million tons of wheat is eaten each year, most of which is milled by large roller mills.

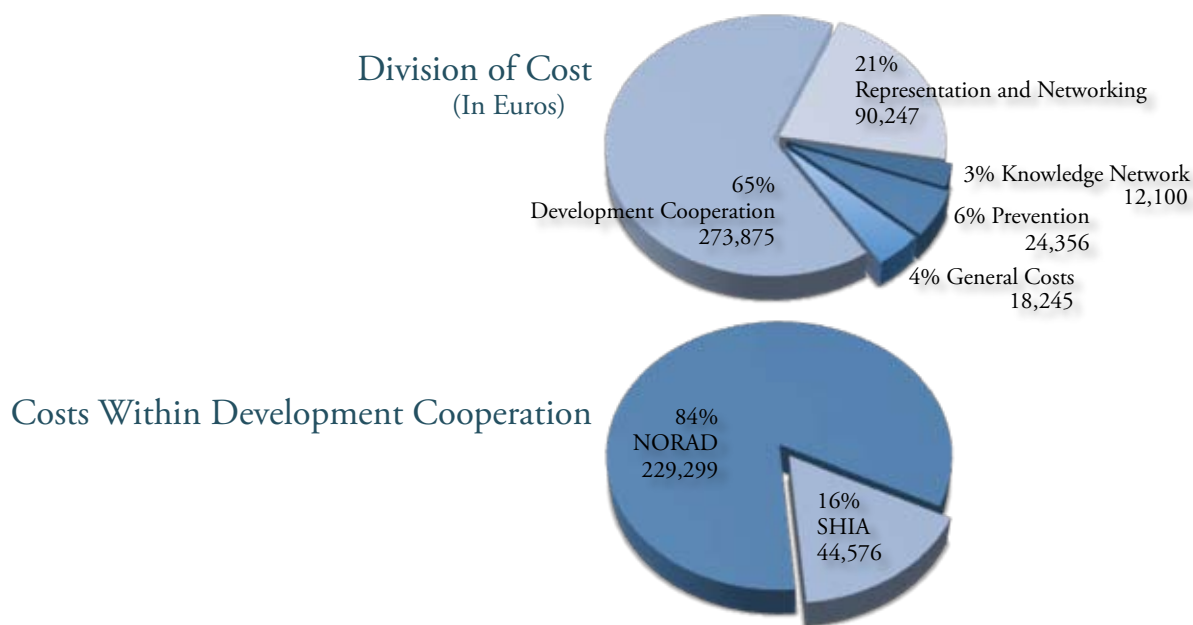
Members of the FFI network - and those whom they can reach and stimulate nationally - have the ability, the resources and knowledge to advance the cause of flour fortification, help save lives, improve the health of millions of the world’s population, and remove a major obstacle to the sustainable development of nations.

2007 was an excellent year and it is with great pleasure that IF looks back. The progress that Flour Fortification Initiative has made is tremendous. That is why they deserve the IF award 2007.

Development Cooperation

IF has been able to develop, with the help of reliable partners, a comprehensive package in treatment and rehabilitation of children with Spina Bifida and Hydrocephalus in six African countries. In 2007, IF and Cure International have developed a training project with Handicap International in Vietnam, executed in the first three months of 2008.

Development Cooperation is, thanks to the partnership with Ryggmargsbrokk- og hydrocephalusforeningen (Norway – RHF) and Riksförbundet för Rörelsehindrade Barn och Ungdomar (Sweden - RBU) that has the support of the Norwegian and Swedish governments (respectively via NORAD and SHIA), the most important activity of IF, counting for 65% of the costs.



IF Funded Projects in East Africa



Some numbers from the projects in Africa:

Surgeries:

- 1367 shunt operations (795 bought in 2007, 1095 bought December 2006 = total 1890 shunts bought)
- 489 ETV-operations in Mbale, Uganda; Dar es Salaam, Tanzania, Kijabe, Kenya, and Lusaka, Zambia
- Follow-up indicators: 85 infections recorded, 48 shunt failures
- 213 Spina Bifida operations (closure of the myelomeningocele and others)
- 1255 other surgical interventions

Total amount of children followed:

- 3963 Hydrocephalus (without Spina Bifida) and 2052 Spina Bifida (with and without Hydrocephalus)
- 1620 children with Spina Bifida and / or Hydrocephalus were seen during clinic days in 2007
- 1559 children in CIC follow-up who receive catheters (of which 295 since January 2007)
- 589 children in bowel management follow-up who receive a cone (of which 108 since January 2007)

Training:

- 30 different training moments for professionals (ranging 1 day to 3 months – can be specified), in total 529 people attending
- 153 people attended conference in Kampala
- 62 different parent meetings: in the RHF / IF projects; 1686 parents attending parent group meetings linked to the RHF/IF-projects
- Continence Management: 21 training days related to projects, 373 people attending (related to target group: professionals, parents, children)

Inclusion:

- 36 children reported to be in school (linked to the parent groups)



Endoscopic Third Ventriculostomy (ETV)

The Zambian neurosurgeon Dr. Kachinga Sichizya was trained by IF Consultant Dr. Benjamin C. Warf at the Mbale Cure hospital in Uganda in Endoscopic Third Ventriculostomy and Choroid Plexus Cauterization (ETV/CPC). With the help of Cure International, he was equipped and the Beit Trust CURE International Hospital of Zambia is now making a real difference for children with Spina Bifida and Hydrocephalus in Zambia.

IF cooperates with Cure Children's Hospital in Mbale to train neurosurgeons in these new techniques. Surgeons from, among others, Nepal, Tanzania, Zambia, Uganda and Vietnam have already been trained and several others (from Bangladesh, Ghana, Ethiopia) are planned.



Dr Kachinga Sichizya presented the technique at the 2008 IF conference in Lisbon.

“For me it is one of the very best innovations to have come in this century,” explains Dr. Kachinga. “The fact that we are able to treat the children with Hydrocephalus without having to put in a shunt - imprisonment to a life-time liability of fear and insecurity - is very special. And when it is successful, you really see the children blossoming, shunt-free and recovering their lost time with physiotherapy and rehabilitation.

During the period of 8 months since the arrival of the endoscopic equipment, up to the month of April 2008, 110 children have undergone ETV/CPC. Of these, 8 returned for re-do surgery. 4 of these 8 patients ended up being shunted. This indicates a success rate of 96.4%. Many other children could not have ETV done for many reasons including bloody CSF, poor anatomy and the scarred cisterns.

My involvement with ETV started when I had an opportunity to join IF and CURE International. Soon after, under the auspices of IF, I was offered a 3 month scholarship at Mbale to learn and practice ETV. It was a wonderful time which I still cherish to this day. I am thankful to my teachers, Dr. John Mugamba and Prof. Dr. Benjamin C. Warf and the staff at Mbale who loved me so much. Working at home in Zambia has been a great fulfillment for me. I am doing some great work which I am thankful for everyday.”

"Suddenly She Appears Among the Trees"

By Renée Höglin, Member IF Board of Directors, Editor RBU Magazine Rörelse

Renée Höglin is board member of IF and closely involved with the work IF does in developing countries. She reports from Uganda when she visited IF projects with her husband.

After travelling in Africa you never entirely leave that continent. A piece of the country you visit follows you forever into the future. Things that stay with you are the red soil, the heat, the crowds of people walking along the roads, the heaps of goods presented everywhere on the ground: bunches of bananas, a handful of tomatoes or a pair of worn-out shoes. Anything that may find a buyer.

The flow of children is etched in your mind and particularly "our" children. Children with Spina Bifida and Hydrocephalus.

After a twelve-day-journey to Uganda, we sit here with an armful of memories, remembering the kindness, the joy in people we met, the high pulsation: as if they cannot afford to waste their lives on grievance. Time is running and people make use of every minute, grateful if there is food and shelter today and tomorrow. In the meantime there are always the children to be taken care of while mum has to work, maybe as a cleaner or a saleswoman in a market place; the children look after each other, a five-year-old taking care of a four-year-old, and in the evening they all have their ration of rice with a green vegetable and some cooked banana.

How will there be time left for the families who have a disabled child to teach him or her to become continent with no smell of urine?

IF is working with several projects in east Africa in which families who have children with Spina Bifida are taught to catheterize their children with the purpose of helping them to become socially continent and not smell from urine. It enables the children to go to school and be with other children.

Deepest in our memory is a little girl of seven whom we met in Mbale, 250 kilometers north-east of Kampala, the capital of Uganda. The girl lives with her mum and a sibling in a tiny house in a typical African slum area. The mother, Kayago Janet, 35, is a widow with seven children aged 7-17 years. Five of them live in another house, the rent of which is paid for by an aunt. Kayago works as a cook in a restaurant. She leaves her home at five in the morning and comes back at six in the evening. The seven-year-old has Spina Bifida and Hydrocephalus and her name is Namutebi Milly. Kayago gave birth to her at home, she saw that the child had a leaking sore in her back and brought her to the district clinic the next day.

From there she was referred to Cure Hospital in Mbale, the only neurosurgical hospital for children in Uganda (23 million inhabitants). Her wound was operated on and healed and Dr. Ben Warf, an American neurosurgeon, said that it might be necessary to operate the child for Hydrocephalus further on. When she was eight months old, it was time for it. He performed what is called an Endoscopic Third Ventriculostomy, ETV; a hole is made at the bottom of the third ventricle in the brain. The good part of this procedure is that no shunt is needed. Shunts often cause complications and are not very suitable in an African setting.





Namutebi Milly, her Mother, and friends

Today, Namutebi can walk without walking aids, she is alert and intelligent - but she is not dry. She cannot control her urine, there are drops falling along her legs. Other children tease her, even beat her. Her mother wants her to start school, but as long as she is incontinent that is impossible.

The social worker from Cure Hospital who has brought us to see this family promises to see to it that the girl will have the opportunity to train self catheterization. It's not enough to demonstrate the CIC method, you have to monitor that it functions in the home environment; either the child must catheterise herself from a certain age or, when parents are at work, the child must be helped by a neighbor or a relative.

When we ask Namutebi what she wishes for her future, she answers smilingly:
- I want money. Lots of money!

Another girl that we met was Joanita in Kampala, the capital of Uganda. We were doing family visits and sat waiting for Joanita to come back from school. Suddenly she appears among the trees, walking very slowly, straight-backed and elegantly, in silence. She wears a neat, red tartan dress, and sits down on a wooden bench in front of the clay hut between her mother and Joan, physiotherapist at Katalemwa Cheshire Home, a rehabilitation centre on the outskirts of Kampala.

A couple of years ago Joanita was very sick, she could hardly walk, let alone go to school, because of a Hydrocephalus, which had gradually grown worse ever since its appearance ten years ago. But only now, at 14, after a fortunate surgical ETV operation carried out in January 2006, she goes to the village primary school together with 8-year-olds, and shows great skill at reading, writing and drawing. She is rapidly catching up, her favorite subject is science, she has learnt a little English, and her dream is to become a lawyer.



Joanita

These two girls, Namutebi Milly and Joanita, stay in our minds, along with many more of "our" children. They need the knowledge and training that come with the IF projects until it's integrated in the services of African caregivers. Africa gives us a perspective on ourselves and the global injustice at the same time as people there convey a cordiality and lust for life that we in the North seldom express.

“PALOPS”

By Mr. Luis Quaresma

Member, IF Board of Directors, Director Associação de Spina Bífida e Hidrocefalia de Portugal (ASBIHP)

Coincidence or not, it was with great joy that on the day of the lunch celebrating the 30th Anniversary of ASBIHP (Associação de Spina Bífida e Hidrocefalia de Portugal), I received a call from Angola inviting me to go to the opening ceremony of the Angolan Association of Spina Bífida and Hydrocephalus. So, in September 2007, I flew to Luanda where I was received by Dr. Mayanda and some representatives of the Angola Health Ministry.

During the five days I was there, I had the opportunity to make a brief presentation about ASBIHP, IF and its projects in East-Africa. I also discussed the possibility to introduce such projects in Angola. All of us are aware of the healthcare scarcity in these African countries, but most of the time we don't know the real dimensions of their reality. And I didn't either, until I arrived there and saw children with very advanced Hydrocephalus, 8 or 9 years old children with Spina Bífida who hadn't been operated on yet...



Mr. Jon Burke, Mr. Tom Baroch and Mr. Luis Quaresma visiting Katalamwa Cheshire Homes in Kampala, Uganda.

At this moment there are 2,000 children with Hydrocephalus, already referred to surgery, waiting for a shunt. If we include the other thousands who live faraway from the capital city, with very few possibilities of having access to healthcare, this number will dramatically increase. I came back from Angola with a richer perception in comparison with the time when I arrived there. I learned, grew up and became conscious that we all have the “opportunity” to try to help, that we are able to do something, and that those projects must be made available in more African countries.

IF immediately sent shunts to Angola and is planning further cooperation.



Human Rights: “People Are Equal”

By Teije Dijk

Treasurer, IF Board of Directors

Chair of the working group Spina Bifida and Hydrocephalus of BOSK, Member of the working group Ethics of BOSK

Each person is unique and has his talents and shortcomings. People are not the same but they are equal. People with a disability are full citizens and have the same rights as everybody else; the right to live, to services, to health-care, to education etc. and the right to participate in social life in all its facets.

IF defends the fundamental human rights of people with Spina Bifida and Hydrocephalus. This has become very necessary because it is no longer self-evident. More and more the right to life for children with these conditions is being contested. The arguments used are that newborns suffer unbearable pains and that the expected quality of life is too poor. This vision is incorrect and based on a one-sided vision on the life with a disability. The IF network makes a stand against this.

1. Right to live.

From a moral and ethical point of view the active termination of life of neonates because they have severe disabilities, is reprehensible and discriminative. It is incompatible with national and international legislation in which the right to live is explicitly guaranteed. That same right also has been included in international treaties, such as the Universal Human Rights Declaration, the Declaration for the Rights of Children and the latest UN Human Rights Convention on the Rights of Persons with Disabilities.

2. The argument of ‘unbearable suffering’ is not applicable for newborns with Spina Bifida.

Advocates for active termination of life argue that neonates with severe Spina Bifida suffer unbearably. However, this has never been scientifically proven. Quite on the contrary, in recent investigations and publications, by, amongst others, Dr. de Jong, have shown that newborns with Spina Bifida are not suffering unbearably. There might be a question of pain, but this can be dealt with effectively.

3. Wrong image of quality of life

Advocates for active termination of life argue that persons with severe forms of Spina Bifida will have a very poor quality of life. The expected quality of life is difficult to predict. Who can determine for someone else what quality of life is acceptable to him? Too often the decision makers on that topic are outsiders; the non-disabled deciding for the disabled.

In 2000, IF brought together 270 people with Spina Bifida and their families from 20 different countries to discuss their quality of life. Together they formulated a powerful resolution on prenatal screening and termination of pregnancy. In another resolution, the IF network reacted on the termination of the lives of newborns with severe forms of Spina Bifida, as proposed in the so-called Groningen Protocol. Both resolutions formed the basis of the two resolutions of the European Disability Forum (EDF) and have widened the debate to all disabilities.



4. Alternatives: treatment and palliative care until passing away naturally

We are of the opinion that all newborns have the right to all available medical treatment that can improve their quality of life or prevent complications. In very serious and complicated situations for which medical treatment is not available and life is not viable, death usually occurs fast and in a natural way. Treatment is no option here and good and respectful palliative care should be offered.

5. Objective information and methods of prevention for parents

Because the unborn child has no legal status, the right to live comes into being after birth. Prenatally, this right to live is not protected. To terminate the pregnancy is proposed to parents when disabilities have been detected. IF pleads that parents should be informed about all aspects of Spina Bifida, also about possible treatments and the improved life expectations. Persons with Spina Bifida and their associations should be involved assuring this information is not outdated or that it is reduced to the medical deficits of living with Spina Bifida.

6. Access to health and all aspects of life

Through the European Disability Foundation (EDF), the IF network was actively involved in the preparation of the UN Convention for the Rights of Persons with Disabilities. The purpose of this convention is to promote, protect and ensure the full and equal enjoyment of all human rights, the fundamental freedoms for all persons with disabilities and respect for their inherent dignity. Through this cooperation, IF not only gives a voice to persons with Spina Bifida in the disability movement but also profits from the rich input of other disability organizations. Resolutions and conventions are tools in the continuous fight for equal rights for the individual with a disability and against segregation and discrimination.

Accessibility does not only imply an accessible environment but also includes an effective educational system, non-discriminatory paid work, payable healthcare, access to life. In many countries Spina Bifida leads to poverty. This should be dealt with. The rights of women with Spina Bifida are another important issue. It is a permanent struggle and the UN Convention on the rights for persons with a disability will be a great help in countries that ratified it.

7. IF's Human Rights activities in 2007

During 2007, IF continued its opposition against applicability of the so-called Groningen Protocol that assumes that physicians are shielded from legal prosecution when they apply active euthanasia on neonates with a serious disability. The 22 documented cases of active termination of life all had Spina Bifida. A medical/ethical commission passes an 'after the fact judgement' whether or not the euthanasia was rightly applied. Also in the Netherlands, this policy is very controversial. IF has voiced its objections underlining the available alternatives towards the Government and medical circles. IF worked closely together with the BOSK organization in the Netherlands to ensure that the voices of parents and persons with Spina Bifida are actively involved in the debate. BOSK is a member of IF and shares IF's opinion.

This issue is not only hitting the headlines in the Netherlands. It also plays in other countries like Italy, Belgium and Slovakia where IF was also involved in the debate by lecturing on conferences, writing articles and participating on debates at universities and in the media.

With its "Tomorrow" conference in Kampala and its active involvement in the Flour Fortification Initiative (FFI), IF promotes primary prevention as the most human and efficient way to prevent Neural Tube Defects.



2007 Through the Eyes of Protagonists

Major Achievements

Aimed at preventing Spina Bifida and Hydrocephalus and improving the quality of life for those with Spina Bifida and Hydrocephalus

IF as an Organization

- IF office opened in Kampala, Uganda
- Foundation of IF Child Help Belgium
- Recognition as EU hosting organization for 3 years

Development Cooperation

- Over 3,000 surgeries, over 6,000 children in follow-up
- Development of the Training Center concept and the International Program for Advanced Treatment of Hydrocephalus project with Cure International (IPATH)
- Continence Management - coordinating expert
- Cooperation with Handicap International in Vietnam

Prevention

- IF - FFI meeting November 8-9, 2007
- Conference on Prevention in Kampala
- European secretariat for prevention network hosted by IF

Human Rights

- UN Convention, focusing on the right to live, right to treatment
- Partnering with the European institutions as NGO representing people with Spina Bifida and Hydrocephalus
- Increasing recognition in Italy and Slovakia

Knowledge Network

- Programming of the Knowledge Network
- Translating Knowledge in 200+ questions and answers
- Development of volunteer network

Financial Stability

- Achieving EU funding for 2008 onwards
- Tax deductibility IF Child Help
- Continuing private donor support
- Pilot actions with members (ASBAH - SBAA)

Members of the International Federation for Spina Bifida and Hydrocephalus

Algeria

Association des malades de Spina Bifida de Mostagenem
villa no83 chemins de crêtes (Mazagran)
Mostagenem 27120
+213 6 99 51 90 36
spinabifida27@yahoo.fr
<http://www.spinabifida27.unblog.fr>

Argentina

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

Australia

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

Austria

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

Belgium

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

Brazil

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

Canada

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

Denmark

Rygmarvsbrokforeningen af 1988
Egebaeksvej 28
8270 Højbjerg
www.rygmarvsbrokforeningen.dk

Estonia

The Estonian MMC and HC Society
Tervise 28
13419 Tallinn

Finland

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

France

Fédération Française des Associations du Spina Bifida
(FFASB)
La Rouère
31440 St Beat
+33 5 61 79 40 78
spinabifida.france@wanadoo.fr

Germany

Arbeitsgemeinschaft Spina Bifida und Hydrocephalus e.V.
Bundesverband (ASBH)
Münsterstr. 13
D-44145 Dortmund
www.asbh.de

Guatemala

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

Ireland

Irish Association for Spina Bifida and Hydrocephalus
(IASBAH)
National Resource Centre, Old Nangor Road
Clondalkin, Dublin 22
www.iasbah.ie

Italy

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

A.S.B.I. Associazione Spina Bifida Italia

Via Duomo n 20
29020 SETTIMA (PC)
<http://www.asbi.info>

Japan

Spina Bifida Association of Japan
Otaku Nakarokugo 4-13-10-214
Tokyo

Luxembourg

Association pour le Spina Bifida a.s.b.l.
5 Chemin de Bousberg, Boite Postale 20
7763 Bissen
+352 85 91 88
spina-bifida@pt.lu
www.ih.lu/spinabifida/index.html

The Netherlands

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Postbus 3359
3502 GJ Utrecht
www.bosk.nl

Norway

Ryggmargsbrokk- og hydrocephalusforeningen
Verkstedett, Bergsalleen 21
0854 Oslo
www.ryggmargsbrokk.org

Peru

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

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

Poland

Stowarzyszenie Chorych z Przepukliną Oponowo-
Rdzeniową R.P. (ASBP)
ul. Nalkowskich 301 a 20-470 Lublin
20-853 Lublin
www.spinabifida.w.interia.pl

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Associação de Spina Bífida e Hidrocefalia de Portugal
(ASBIHP)
Rua Botelho de Vasconcelos, Lote 567 C/D
1900-637 Lisboa
asbihp@sapo.pt
www.asbihp.rcts.pt

Romania

Asociația Română de Spina Bifida și Hidrocefalie
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Russia

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

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

Slovakia

Slovenská spoločnosť pre Spina Bifida a/ alebo Hydroce-
falus, o. z.
SNP 14
911 04 Smolenice
www.sbah.sk

Spain

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

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

Sweden

Riksförbundet för Rörelsehindrade Barn och Ungdomar
(RBU)
Box 8026, S:t Eriksgatan 44, 4 tr
104 20 Stockholm
www.rbu.se

Switzerland

Schweizerische Vereinigung zugunsten von Personen mit
Spina Bifida und Hydrocephalus (SBH)
Geschäftsstelle SHB CH, Schulrain 3,
6276 Hohenrain
www.spina-hydro.ch

Turkey

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

UK

Association for Spina Bifida and Hydrocephalus (ASBAH)
ASBAH House, 42 Park Road
Peterborough PE1 2 UQ
helpline@asbah.org
www.asbah.org

USA

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

Financial Results in 2007

Statement of the Auditor:

REPORT OF THE AUDITOR ON THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 31-12-2007 ADDRESSED TO THE GENERAL MEETING OF "INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS"

(Cellebroersstraat 16 – 1000 Brussels)

In accordance with the assignment by the board of directors, we report to you on the performance of the audit mandate which has been entrusted to us.

We have audited the financial statements for the year ended 31-12-2007, prepared under the responsibility of the board of directors of the federation, which show a balance sheet total of € 318.257,53 and a loss for the year of € 41.476,73.

UNQUALIFIED AUDIT OPINION ON THE FINANCIAL STATEMENTS

Our audit was planned and performed to obtain reasonable assurance about whether the financial statements are free of material misstatement.

Federation officials have responded clearly to our requests for explanations and information.

On a test basis, we have examined the justification for the amounts included in the annual accounts. We have assessed the accounting policies, the significant accounting estimates made by the federation and the overall financial statement presentation.

We believe that our audit provides a reasonable basis for our opinion.

In our opinion, taking into account the legal and regulatory requirements applicable in Belgium, the financial statements for the year ended 31/12/2007 give a true and fair view of the federation's assets, liabilities, financial position and results of operations.

ADDITIONAL CERTIFICATIONS AND INFORMATION

We supplement our report with the following certifications and information which do not modify our audit opinion on the financial statements:

Without prejudice to formal aspects of minor importance, the accounting records were maintained in accordance with the legal and regulatory requirements applicable in Belgium.

Otherwise, we do not have to report to you any transactions undertaken or decisions made in violation of the bylaws or the articles of the Law on Non-Profit Organizations.

Lennik, March 25th 2008
BVBA De Nul & co
Auditor

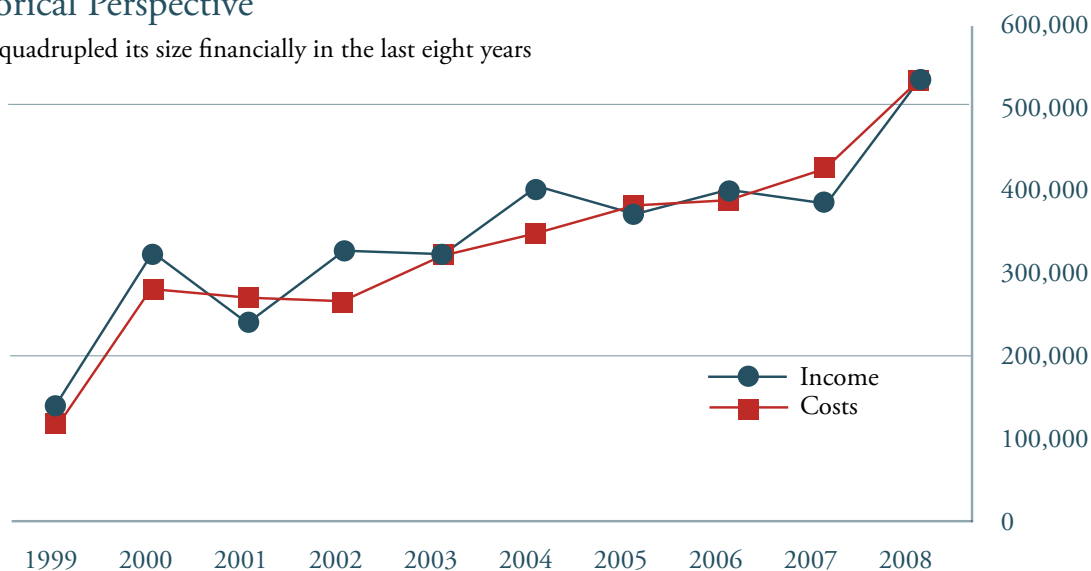
Signed and represented by
Roger De Nul

Balance sheet at 31 December 2007 (in Euros)

Assets		31-Dec-07	31-Dec-06	Liabilities		31-Dec-07	31-Dec-06
TANGIBLE ASSETS		2,347.64	3,098.48	RESERVES		294,608.40	336,085.13
Investments		12,547.80	11,548.80	Funds of IF		336,085.13	324,513.53
Depreciations investments		-10,730.95	-8,981.11	Profit-losses reported		0.00	0.00
Cautions		530.79	530.79	Profit-loss bookyear		-41,476.73	11,571.60
AMOUNTS RECEIVABLE		42,776.59	22,792.59	AMOUNTS PAYABLE		23,649.13	52,774.72
Customors		10,045.06	3,018.73	Suppliers		9,046.37	37,479.06
Projects current accounts		800.00	6,412.45	Invoices to receive		0.00	2,743.22
Divers to receive		1,933.16	0.00	Salary's to be paid		0.00	688.53
Donations KBS to receive		0.00	12,224.07	Provision holiday fee		11,342.94	9,407.91
IF Child Help current account		29,998.37	1,137.34	Divers debts (rent)		0.00	2,456.00
				Projects current accounts		3,259.82	0.00
BANK & CASH ACCOUNTS		270,032.34	361,995.89	TRANSIT ACCOUNTS		0.00	0.00
Stocks		198,750.25	207,626.45	Profits for next year		0.00	0.00
KBC - accounts		12,832.52	5,075.81				
KBC - accounts saving		57,869.16	149,293.63				
Pay pal		580.41	0.00				
Internal transfers		0.00	0.00				
TRANSIT ACCOUNTS		3,100.96	972.89				
Costs for next year		3,100.96	972.89				
Total Assets		318,257	388,859	Total Liabilities		318,257	388,859

Historical Perspective

IF has quadrupled its size financially in the last eight years



Profit and Loss Statements (in Euros)

Costs

Diverse costs	283,942.68
Rent office	6,838.55
Energy	1,021.04
Office supplies	2,618.65
Publications - copy	2,262.05
Documentation - books	679.81
Website	12,669.67
Telephone - fax - mail	2,659.52
Postal costs	172.35
Transporters	1,315.79
Membership fees	120.00
Fee translator	463.80
Fee bookkeeper	2,422.55
Fee auditor	1,603.25
Fee social secretary	1,115.38
Fee medical secretary	221.32
Other fees	196.02
Insurance	1,003.12
Transport expenses	34,363.41
Official documents (visas)	547.76
Representation	7,920.81
Medical material projects	19,340.33
Salary's in projects	62,708.63
Training projects	28,215.00
Other expenses projects	46,231.10
Conferences - meetings	47,232.77
Salary	132,413.14
Gross salary	85,842.88
13th month	3,313.52
Holiday fee	9,145.24
Transport home-work	2,722.00
Forfait costs	3,350.00
Social charges	25,380.53
Provision holiday fee	1,935.03
Insurance personnel	723.94

Depreciations	1,749.84
Depreciations	1,749.84
Financial costs	3,460.91
Bank charges	3,122.15
Payment & change differences	210.90
Change differences	127.86
Exceptional costs	2,048.73
Exceptional costs	2,048.73

Total costs 423,516

Income

Membership fees, donations & subsidies	306,801.15
Membership fees	6,040.00
Donations - fundraising	3,662.25
Other grants	30,469.96
Subsidies project Norad	226,573.94
Subsidies project SHIA	39,055.00
Subsidies project other	1,000.00
General income	69,607.04
Recuperation salary costs	66.26
Diverse recuperation	69,540.78
Financial income	5,730.38
Financial products	3,563.38
Payment differences	62.83
Change differences	2,104.17

Total Income 382,138

Net Result -41,476

Profit and Loss 2007 Memo by Mr. Teije Dijk, treasurer of IF Board of Directors; Mr. Pierre Mertens, IF president and Mr. Lieven Bauwens, IF General Coordinator

The IF Board decided in the budget 2006 to invest 50,000 € in the financial stability of IF to achieve a sustainable situation for IF's future.

This explains the deficit of -41,476.73€. But it resulted in direct results for 2008. IF made the strategic choice not to invest in a fundraising professional, but instead IF invested in content and existing contacts at the European Commission and the Flour Fortification Initiative (FFI). IF made the basis for fundraising in Belgium by creating IF Child Help and by achieving the official status for fiscal deduction of gifts.

The last years, there has been a constant increase in the demand in our projects in Africa (medical material, personnel, trainings, outreach clinics, operations ...) without a growing fundraising base. However, there have been initiatives taken to increase the fundraising base:

1. Foundation of IF Child Help Belgium, resulting very recently in the tax deductibility status (Government decision taken 23 April 2008). IF Child Help can now start the process for Belgian and European fundraising for the developing cooperation programs.
2. Cooperation with ASBAH on fundraising in UK started January 2008, addressing trusts and foundations specifically for Development Cooperation. Evaluation in a couple of months, ultimate goal: IF Child Help UK with relations with the government.
3. Cooperation with Cure International on joint projects such as International Programme for Advanced Treatment of Hydrocephalus (IPATH - training programme and centre in Kampala for Endoscopic Third Ventriculostomy)
4. Cooperation with Handicap International towards a training project in Vietnam.
5. IF opened an Office in Kampala employing two staff members. IF got a free of charge office facilities in AVSI, an Italian NGO

IF realized a lot in 2007. Investment of -41,476.73€ in core topics resulted in an increase in resources that seem to be sustainable (125,000€ at the European Commission: at least three years, renewable; FFI: investment in European coordination office hosted by IF). The investment did not affect the healthy financial situation of the organization.

The projects in cooperation with RHF and RBU (NORAD and SHIA) are also sustainable for the coming 2 (or more, in case of NORAD) years. This allows IF to raise funds in a more structured and less frantic way. More confidently. Overhead is spread over more projects, alleviating the burden on the relatively small projects of development cooperation.

Seen the efforts already pursued in 2008, the investment worked well. IF should further invest in development of the own organization. More input in development of the development cooperation department is needed. And of course all support is welcome.

International Institutions



International Partnerships



Other International NGOs



Companies



Photography: p5, 8,15, 19, 22, 23, 25, 26, 27 Zjuul Devens; p6 Renée Jopp; p29 Margrethe Svedal
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The seven-year Programme targets all stakeholders who can help shape the development of appropriate and effective employment and social legislation and policies, across the EU-27, EFTA and EU candidate and pre-candidate countries.

To that effect, PROGRESS purports at:

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

The information contained in this publication does not necessarily reflect the position or opinion of the European Commission.



European Commission
Directorate-General Employment, Social Affairs and Equal Opportunities
Integration of People with Disabilities - Unit G3



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

International Federation for Spina Bifida & Hydrocephalus

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

Participatory status, Council of Europe.

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