

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

"Access" Activity report 2006

Presented on and accepted by the General Meeting of the International Federation for Spina Bifida and Hydrocephalus

26 May 2007

Munyonyo Speke Resort Munyonyo, Kampala, Uganda

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This is a working document. After adoption at the General Meeting, the office will make sure there is a graphic interesting publication to be used in our external communication.

Introduction

'The future is now'.

Most parents of children with Spina Bifida and Hydrocephalus know this already. Parents work on a long-term project called 'education'. Access to adulthood starts very early in a child's life by informing and involving the child in everything that concerns him or her. Parents and professionals who, with the best of intentions, overprotect the children, create dependent and demanding adults. Only children who are given responsibility as soon as they are ready for it, will be able to make a successful transition from childhood to adulthood, becoming adults who take care of their own life and health. Parents grow seeds early for the child to reap later.

"Access" was the theme of our 2006 conference in Helsinki where we shared with each other the best there is for our children and a growing group of adults with Spina Bifida and Hydrocephalus.

Nowadays, young children with Spina Bifida and Hydrocephalus have a better start: the treatment and care of children and adults with Spina Bifida has shown tremendous progress during recent decades, mainly because of the system of interdisciplinary care. Their quality of life has improved considerably, too: 90% of the babies reach adult age and 80% of them have a normal IQ; nearly all become socially dry, despite problems with incontinence. Due to the IF projects this success is made available to our friends in the South where we sometimes have even better results than in the North.

More and more adults with Spina Bifida take their place in society. We also notice this in IF where they determine policy within their organizations and also become leaders, including presidents. They study, work, become parents themselves, and grow old. Within IF we know of several physicians, lawyers, and others, including a government minister who have a severe form of Spina Bifida. In Belgium, we know of an 83 year old man with Spina Bifida who is in good health and is planning to go to his nineties. Research in the Netherlands and Norway has shown that young adults with Spina Bifida rate their quality of life higher than their peers without impairment. Their lives are not always easy but they appear to get more out of it. Undoubtedly this success story is the result of good co-operation between parents, determined adults, devoted physicians and last but not least self help groups and associations in the various countries of the IF-network.

This does not mean that we reached all our goals. Not all of these successful adults get a good job, they do not have access to good public transport, they don't always get access to the right information on their medical condition, nor is sufficient consideration taken to the status of each individual's cognitive status; good interdisciplinary care for children is not continued for adults; future mothers do not get access to the necessary doses of folic acid and pregnant women get incorrect information on the condition of their unborn child, not all unborn children with Spina Bifida and Hydrocephalus get access to life and the available treatment.

Our success story is in danger through the systematic elimination of children with Spina Bifida after prenatal diagnosis. More than ever our associations in the network have to stand up and fight to safeguard what we achieved. The knowledge and expertise we have built up during past decades is at risk, disappearing together with our devoted doctors when they retire. Very few young doctors are coming in, because their target group decreases and they believe 'the problem is solved'. Should Spina Bifida teams be supported if the impairment can be prevented? Prevented is an elegant way to say eliminated.

Major efforts have been made in 2006 on primary prevention and ethics resulting in two new IF resolutions: one on mandatory food fortification and one on the right to access to life and treatment for newborns with Spina Bifida.

The IF network plays an important role in safeguarding the quality of interdisciplinary care, avoiding unnecessary use of high tech medicine when interventions and investigations are economically profitable but do not contribute to a better quality of life.

The IF network ensures that quality controlled knowledge is kept, developed and made available to all. Information is a mouse-click away for many people today. But Internet has its danger. Not all information on the web is reliable and IF ensure that we build with and for our network on a quality controlled information bank.

Our success makes us strong and we can be proud of it. Our voice needs to be heard and together we can succeed. We have to stand up as full and responsible citizens. We are not a complaining dissatisfied, dependent and demanding minority. We take on responsibility, cooperating in further research on the real causes of Spina Bifida and Hydrocephalus and contributing to better care; promoting primary prevention, putting ourselves on the agenda of policymakers and International NGO's. The IF network shows solidarity with the South in its projects for early detection, treatment and rehabilitation of Spina Bifida and Hydrocephalus in developing countries. We have something to tell to the world!

Spina Bifida and Hydrocephalus associations in the IF network are needed more than ever. The future is now, together we have access to it.

Pierre Mertens

President IF network

Report to the board and the general meeting 2006

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.

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 32 full member organisations: Spina Bifida and/or Hydrocephalus organisations of Australia, Austria, Argentina, Belgium, Brazil, Denmark, Estonia, Finland, France, Germany, Guatemala, Ireland, Italy, Japan, Luxembourg, the Netherlands, Norway, Peru, Poland, Portugal, Russia, 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, together with its Norwegian and Swedish member associations, 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.

IF Board

- × Mr Pierre Mertens, President
- × Mrs Eli Skattebu, Vice-president
- × Mr Teije Dijk, Treasurer
- × Mrs Cindy Brownstein
- × Mrs Renée Höglin
- × Mr Jon Burke
- Mr Luis Quaresma
- × Mrs Vicky Sandoval
- × Ines Orella Sáenz, resigned after election

IF Staff

- × Mr Lieven Bauwens
- × Mrs Els De Clercq
- × Mrs Marja Pia Wurzer

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
- × Mrs Renée Jopp, multimedia and photography
- × 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
- imes Dr Benjamin C. Warf.; medical consultant IF, paediatric neurosurgeon, ABNS, ABPNS

Activity Report

Structure of this report

The activities of IF during the past year are structured around 6 domains: IF as Network, IF Development Cooperation (IF DC), IF Ethics and Human Rights (IF HR), IF Prevention (IF PR), IF Knowledge Network (IF KN) and IF as Organisation.

| IF as Network | IF as Organisation | IF DC | IF HR | IF KN | IF PR |
|--|---|--|--|--|--|
| Activities related to IF as a membership and volunteering organisation. × Conferences × Meetings | Activities related to running an independent organisation × Staff / Human resources × Legal issues × Fundraising × Networking | Activities in development cooperation × IF projects × Sensitization in the North × Fundraising × Adaptation of material × Networking (see attached documents) | Activities related to IF as a human rights advocate × Lectures × Publications × Conferences | Activities related to the implementation of the digital Knowledge Network | Activities related to primary prevention: × Mandatory Food Fortification ○ Sensitization ○ Support ○ × Folic Acid ○ Campaigns ○ |

The report is a list of activities, sorted according the domain and the date.

Report

| Domain | Date (mm/ yy)? | Type of activity? | More information | Where? | Result: what? | More information | Result: how much? | Who? |
|---------------|----------------|-------------------|--|----------------------|---------------|--|-------------------|----------|
| IF as Network | 01/06 | Other | Newsflashes in 2006: English - 30 January 2006 - 19 April 2006 - 7 May 2006 - 19 July 2006 - 1 September 2006 - 27 October 2006 - 2 December 2006 - Spanish: 12 December 2006 - | Brussels, Belgium | Publication | growing number of subscribers (beginning 2006 about 2800, now about 3300) | | IF staff |

| | Date (mm/ | Type of | | | | | Result: how | |
|---------------|--------------|------------|--|-------------|---------------|------------------------------|-------------|----------------|
| Domain | yy)? | activity? | More information | Where? | Result: what? | More information | much? | Who? |
| | | • | | | | | | |
| | | | | | | | | |
| | | | | | | | | |
| | | | Dutch: 15 February 2006 - 12 April 2006 | | | | | |
| | | | Liaison Officer newsletter | Brussels, | | | | |
| IF as Network | 01/06 | Other | March, September | Belgium | Publication | | | IF staff |
| | | | | Brussels, | (electronic) | Growing number of hits | | |
| IF as Network | 01/06 | Other | Website | Belgium | publication | and individual visits | | IF staff |
| | | | | | | | | Renée Höglin, |
| _ | | _ | about trip to Tanzania and | Stockholm, | | in RBU membership | | editor of |
| IF as Network | 01/06 | | Kenya, by dr. Sofia Dettman | Sweden | Publication | magazine Rorelse | | Rorelse |
| | | Speech / | | Mumbai, | | | | |
| IF as Network | 02/06 | lecture | presentation on IF network | India | Contact | | | Pierre Mertens |
| | | | support and start parent group | Mumbai, | | | | |
| IF as Network | 02/06 | Other | Mumbai | India | Contact | | | Pierre Mertens |
| | | | | | | Study visit – training | | |
| | | | | | | Visit to Capitol Hill (House | | |
| | | | | Washington, | | and Senate together with | | |
| IF as Network | | | Visit of SBA – US-member of IF | USA | Cooperation | SBA) | | Lieven Bauwens |
| IF as Network | 04/06 | Visit | Visit of SB&H, Canada | Canada | Contact | With Steve Keane | | Renée Höglin |
| | | | meeting Chinese umbrella | | | | | |
| IF as Network | 05/06 | Visit | organisation for PwD | China | Contact | | | Pierre Mertens |
| | | | | | | 5 new members (Italy, | | |
| | | | | Brussels, | | Argentina, Brazil, Peru, | | |
| IF as Network | , | | Membership | Belgium | Membership | Russia) | | |
| IF as Network | 06/06 | Conference | International Conference | Helsinki, | Other | Lectures from the | | IF board and |
| | | | | Finland | | International Network: | | staff |
| | | | | | | Renée Höglin (on | | CP-liitto |
| | | | | | | Transition to adulthood), | | |

| | Date | Turns of | | | | | Result: how | |
|----------------|--------------|-------------------|---|------------|---------------|----------------------------|--------------|----------------------------|
| Domain | (mm/ yy)? | Type of activity? | More information | Where? | Result: what? | More information | much? | Who? |
| | | | | , 51516161 | , 23300000 | | , 53500 0150 | , |
| | | | | | | Klaus Seidentucker, Pierre | | |
| | | | | | | Mertens – IF award to Mr | | |
| | | | | | | Bo Hjelt | | |
| | | | | | | Elections for board | | |
| | | | | | | members – acceptance of | | |
| | | | | Helsinki, | | resolution – presentation | | IF Board and |
| IF as Network | 06/06 | Meeting | General Meeting | Finland | Membership | demo Knowledge Network | | staff |
| IF as a | | | | Helsinki, | | | | If Board and |
| Network | 06/06 | Meeting | Liaison Officer Meeting | Finland | | | | staff |
| | | | Meeting with Lisbeth Bahl- | | | | | |
| IC as Naturali | 07/06 | NA+: | Poulsen, officer at European | Durranala | Cambaat | | | Lieven Deverse |
| IF as Network | 07/06 | Meeting | Commission | Brussels | Contact | | | Lieven Bauwens |
| | | | Articles on General Meeting and | | | | | Renée Höglin, editor of |
| IF as Network | 09/06 | Articles | conference in Rorelse | Sweden | | | | Rorelse |
| ii as Network | 02/00 | Aiticles | Visit and lecture of Pierre | Jweden | | | | Noteise |
| | | | Mertens on the 10 th anniversary | | | | | |
| IF as Network | 09/06 | Visit | of the Polish SB/H association | Poland | | | | Pierre Mertens |
| IF as Network | | Meeting | Preparation conference 2007 | Uganda | | | , | Lieven Bauwens |
| | | | Els De Clercq on maternity and | | | | | |
| | | | maternal leave until 11 | | | | | |
| IF as | | | September 2006, from 15 | Brussels, | | | | |
| Organisation | 01/06 | Other | December 2006 working 4/5. | Belgium | | | | |
| IF as | | | Board meeting 12-15 January | Lisbon, | | | | IF Board and |
| Organisation | 01/06 | Meeting | 2006 | Portugal | | | | Lieven Bauwens |
| IF as | | | | Brussels, | | | | IF Staff and |
| Organisation | 01/06 | Meetings | Staff meetings | Belgium | | | , | Pierre Mertens |
| | | | | | | Cindy Brownstein, Teije | | |
| IF as | | | Management committee | Brussels, | | Dijk, Bo Hjelt and Pierre | | IF Management |
| Organisation | 01/06 | Meeting | meeting | Belgium | | Mertens | | Committee |

| | Date | T | | | | | D 4 . | |
|--------------|--------------|-------------------|-----------------------------------|-------------|---------------|-----------------------------|-------------------|---|
| Domain | (mm/ yy)? | Type of activity? | More information | Where? | Result: what? | More information | Result: how much? | Who? |
| IF as | yy /• | activity. | financial and activity report | Belgium, IF | nesure. What. | annual report as required | macii. | *************************************** |
| Organisation | 02/06 | Other | 2005 to NORAD | office | Report | by NORAD | | Lieven Bauwens |
| | | | | , | | | Used by | , |
| | | | | | | | Norad, Shia, | |
| | | | Auditing of the accounts by | | | | General | |
| | | | registered auditor Roger De Nul | | | | Meeting, | |
| IF as | | | bvba and Gert Van Bavel, | Brussels, | | | application | |
| Organisation | 03/06 | Other | bookkeeper | Belgium | Report | Auditing report | to the EU | |
| IF as | • | • | Meeting with Luc Dekesel, | Brussels, | | | | |
| Organisation | 05/06 | Meeting | fundraising expert CBM | Belgium | | | | Lieven Bauwens |
| IF as | • | • | | Brussels, | | | | |
| Organisation | 05/06 | Other | IF Annual Report | Belgium | Report | Annual report 2005 | | IF Staff |
| IF as | | | Meeting with Luc Dekesel, | Brussels, | | Development of a | | |
| Organisation | 06/06 | Meeting | fundraising expert CBM | Belgium | Other | fundraising letter | | Lieven Bauwens |
| | | | | | | | Tax- | |
| | | | | | | | deductibility | |
| | | | | | | | is possible | |
| | | | | | | Follow-up contacts with Mr | | |
| | | | | _ | | Warmoes and Mrs | from 5.000 | |
| IF as | | | Fundraising in US-seminar by | Brussels, | | Dehandschutter on | USD | |
| Organisation | 06/06 | Seminar | KBS | Belgium | Contact | fundraising in the US | onwards | Lieven Bauwens |
| IF as | | | Participation with staff at the | Brussels, | | Also participation in site- | | |
| Organisation | 06/06 | Other | celebration of the office site | Belgium | | video | | |
| | | | Hiring Miek Van den Stock as | | | | | |
| | | | temporary staff (15 June to 15 | | | | | |
| | | | September 2006) in order to | | | | | |
| | | | prepare for the General | | | | | |
| | | | Meeting, start of the Knowledge | | | | | |
| | | | Network, picking up the | | | | | |
| IF as | | | practicalities of the fundraising | Brussels, | | | | |
| Organisation | 06/06 | Other | campaign in the summer | Belgium | | | | |

| | Date (mm/ | Type of | | | | | Result: how | |
|----------------|--------------|-------------|------------------------------------|--|---------------|--|-------------|----------------|
| | yy)? | activity? | More information | Where? | Result: what? | More information | much? | Who? |
| IF as | | | Fundraising effort – letter | Brussels, | | By volunteer Annie Van | 300 | |
| Organisation | 08/06 | Meeting | campaign to existing contacts | Belgium | , | Thienen | addresses | |
| | | | Publication Magazine of the | | | | | |
| IF as | | | Flemish Spina Bifida | Brussels, | | 400 letters in Flemish Spina | | Miek Van den |
| Organisation | 08/06 | Fundraising | organisation | Belgium | Other | Bifida magazine | | Stock |
| | | | Publication Tertio / Dimanche: | | | | | |
| IF as | 00/01 | | fundraising campaign in | Brussels, | | 20.000 letters in Flemish | | Miek Van den |
| | 08/06 | Fundraising | cooperation with Luc Dekesel | Belgium | Other | and Walloon magazine | | Stock |
| IF as | 00/06 | | Meeting with SN Brussels | Brussels, | . | | | 5 |
| Organisation | 09/06 | Meeting | Airlines | Belgium | Cooperation | Conference carrier | | Lieven Bauwens |
| 15 | | | 6 1 7 6 | ъ . | | Zsofia found a job and did | | |
| IF as | 00/06 | NA | Several meetings with Zsofia | Brussels, | | not take a position as | | |
| | 09/06 | Meeting | Szendrey, possible volunteer | Belgium | | volunteer | | |
| IF as | 00/06 | Othor | Move of the IF office to office 19 | Brussels, | Othor | manya anatiawa affica | | IF Staff |
| Organisation | 09/06 | Otner | in the same building | Belgium | Other | more spatious office | | IF Staff |
| | | | | | | Founding members: IF, | | |
| | | | | | | Pierre Mertens, prof. Patrick Devlieger, prof. Emmanuel | | |
| | | | | | | Keirse, Joris Petillion, | | |
| | | | | | | Lieven Bauwens – Board | | |
| | | | | | | members: Pierre Mertens, | | |
| | | | Foundation of IF Child Help | | | prof. Patrick Devlieger, | | |
| | | | Belgium, separate Belgian | | | prof. Emmanuel Keirse, | | |
| IF as | | | Development Cooperation | Brussels, | | Joris Petillion, Lieven | | |
| | 09/06 | Other | organisation | Belgium | Other | Bauwens and Marcel Kerff | | |
| Organisation . | 0,00 | Carci | Evaluation meeting with Luc | Deigiani | Carci | Daarrens and Marcen Rem | | |
| IF as | | | Dekesel on summer fundraising | Brussels, | | | | |
| | 10/06 | Meeting | action | Belgium | | | | Lieven Buwens |
| : ga | , | | | <u>_ = = : g : - : : : : : : : : : : : : : : : : : : :</u> | | | | Lieven Bauwens |
| IF as | | | Sponsor prospectus conference | Brussels, | | | | and Cindy |
| Organisation | 10/06 | Fundraising | 2007 | Belgium | Publication | Sponsoring prospectus | | Browstein |

| | Date (mm/ | Type of | | | | | Result: how | |
|-----------------------|--------------|-------------|-----------------------------------|-------------|---------------|---|------------------|----------------|
| Domain | yy)? | activity? | More information | Where? | Result: what? | More information | much? | Who? |
| | , , , , | | Meeting at EDF on the | | | | | |
| | | | development of a European | | | | | |
| IF as | | | project in the Progress budget | Brussels, | | | | |
| Organisation | 10/06 | Meeting | line | Belgium | | | | Lieven Bauwens |
| | | | | | | Expanded application, consisting of legal | | |
| | | | | | | documents, work plan | | |
| IF as | | | Application to the EU, Progress | Brussels, | | 2007 (excl. Development | | |
| Organisation | 11/06 | Application | Action 3: VP2006/019/342 | Belgium | Application | Cooperation) | | IF Staff |
| | | | Meeting with Bo Hjelt, IF expert | | | | | |
| | | | and founder of CDI foundation | | | | | Lieven Bauwens |
| IF as | | | (investing in research into Spina | | | | | and Els De |
| Organisation | 11/06 | Meeting | Bifida and Hydrocephalus) | Belgium | | | | Clercq |
| | | | | | | | Not . | |
| | | | | | | | accepted | |
| ·- | | | A 1: .: E | ь . | | C AFC UNIT | because | |
| IF as | 11/06 | ۸ا: معد: م | Application European Voluntary | Brussels, | Carata at | Contact with AFS - JINT - | "too | Lieven Deverse |
| Organisation | 11/06 | Application | Service | Belgium | Contact | VIA | difficult" | Lieven Bauwens |
| IF as | 12/06 | Other | Fundraising effort – letter | Veurne | | By volunteer Annie Van Thienen | 550 addresses | |
| Organisation IF as | 12/00 | Other | campaign to existing contacts | veume | | menen | addresses | Lieven Bauwens |
| Organisation | 12/06 | Fundraising | Meetings with B Braun – Merck | Belgium | Contact | Prospects sponsoring | | and Pia Wurzer |
| IF as | 12/00 | rundiaising | Meetings with b bradit - Merck | The | Contact | 1 Tospects sponsoring | | By Teije Dijk |
| Organisation | 12/06 | Fundraising | Christmas letter action Bosk | Netherlands | | | | and Bosk |
| | , 00 | | IF Fact Sheets (General - | | , | | | |
| | | | Development Cooperation - | | | | | |
| | | | Human Rights - Prevention - | | | | | |
| IF as | | | Knowledge Network - | Brussels, | | | | |
| Organisation | 05/06 | Other | Mandatory Food Fortification) | Belgium | Publication | Fact Sheets version 1 | | IF Staff |

| | Date (mm/ | Type of | | | | | Result: how | |
|--------------|--------------|---------------------------------------|----------------------------------|--------------|---------------|--|--------------|------------------|
| Domain | yy)? | activity? | More information | Where? | Result: what? | More information | much? | Who? |
| | | · · · · · · · · · · · · · · · · · · · | IF Fact Sheets (General - | | | | | |
| | | | Development Cooperation - | | | | | |
| | | | Human Rights - Prevention - | | | | | |
| IF as | | | Knowledge Network - | Brussels, | | | | |
| Organisation | 08/06 | Other | Mandatory Food Fortification) | Belgium | Publication | Fact Sheets version 2 | | IF Staff |
| | | | Dr Carla Verpoorten to Norway | | | | | |
| | | | to prepare evaluation projects, | | | | | |
| | | | discussions with representatives | | | | | |
| | | | of Norwegian member | | | and the control of th | | |
| IE DC | 01/06 | Frank and an | association RHF and Eva E. | NI | Danasat | will result in report on | | |
| IF DC | 01/06 | Evaluation | Naess | Norway | Report | evaluation | 40.000 C | |
| | | | Negotiate and work out plan for | Namaal | | | 40.000 € per | |
| IE DC | 01/06 | F duaisia a | Mantana grant (private | Norway and | Othou | | year for IF | |
| IF DC | 01/06 | Fundraising | donation) | IF office | Other | | projects | |
| IF DC | 02/06 | Training | Training parents CIC | Mumbai | Other | | | |
| IF DC | 02/06 | Training | management | Vietnam, | Other | implementation protocol | | |
| IF DC | 02/06 | Training | Training CIC management | India | Cooperation | in HI Vietnam project | | |
| IF DC | 02/00 | Training | Training Cic management | iliuia | Cooperation | iii ii vietilaili project | | Renée Höglin, |
| | | | | | | | | Eva Toft, Karin |
| | | | | SHIA office, | | Discussion about capacity | | Berggren and |
| | | | SHIA meeting with Mr Borje | Stockholm, | | building of parents in | | Anu Ala-Rantala |
| IF DC | 02/06 | Meeting | Fors for, Saturday 11/2/06 | Sweden | other | Moshi and Dar | | (SHIA) |
| | 02,00 | Meeting | financial and activity report | Brussels, | Other | annual report as required | | (31 117 1) |
| IF DC | 02/06 | Other | 2005 to SHIA | Belgium | Report | by SHIA | | |
| | | | visit projects Handicap | | | , | | |
| IF DC | 02/06 | Visit | International | Vietnam | Cooperation | | | |
| IF DC | 03/06 | Meeting | working meeting with RBU and | Stockholm, | Report | evaluation report 2005 | - | Pierre Mertens, |
| | | | SHIA | Sweden | • | · | | Lieven |
| | | | | | | | | Bauwens, Anu |
| | | | | | | | | Ala-Rantala, Eva |
| | | | | | | | | Toft, Karin |

| | Date (mm/ | Type of | | | | | Result: how | |
|---|--------------|-------------|--|------------|---------------|--------------------------|--------------|--|
| Domain | yy)? | activity? | More information | Where? | Result: what? | More information | much? | Who? |
| | | | | | | | | Berggren, Björn Rundström and Renée Höglin |
| | | | working meeting with RBU and | Stokholm, | | Preparation application | | - |
| IF DC | 03/06 | Meeting | SHIA | Sweden | Other | 2007-2009 | | |
| | | | project results 2006 see | | | | | |
| IF DC | 03/06 | Other | separate report below | | Other | | | |
| | | | Visit by Njål Lovik, treasurer | | | | | |
| | | | Norwegian organisation, audit | Brussels, | | | | |
| IF DC | 03/06 | Visit | of 2005 result | Belgium | Other | | | |
| | | | visit HI program – lecture for HI co-workers – visit orphanages | | | | | |
| | | | Beijing and Xian – visit hospital | Xian and | | | | |
| | | | traditional medicine plus | Beijing, | | | | |
| IF DC | 05/06 | Visit | lecture | China, | Cooperation | | | |
| <u>" " " " " " " " " " " " " " " " " " " </u> | 03/00 | VISIC | Meeting with Sophie Beaumont, | Brussels, | cooperation | | , | |
| IF DC | 05/06 | Meeting | Light for the World | Belgium | Contact | | | |
| | | | | | | | agreed | Renée Höglin, |
| | | | | | | | budgets: | Karin Berggren, |
| | | | | | | | 2007:39.163 | Björn |
| | | | | | | | €-2008: | Rundström, Eva |
| | | | | | | | 39.163€- | Toft, Lieven |
| | | | | Brussels, | | | 2009: 39.163 | Bauwens, Pierre |
| IF DC | 06/06 | Application | application SHIA 2007-2009 | Belgium | | | € | Mertens |
| | | | Eva Elisabeth Naess to Belgium | Brussels, | , | will result in report on | | |
| IF DC | 06/06 | Evaluation | to prepare evaluation projects | Belgium | | evaluation . | | |
| | | | | | | | | Ann-Eli Spiten, |
| | | | Preparation meeting for | | | | | Eli Skattebu, |
| | | | application NORAD | | | | | Njål Lovik, |
| | | | | | | | | Pierre Mertens |
| | | | Preparation meeting Evaluation | Stavanger, | | | | and Lieven |
| IF DC | 06/06 | Meeting | of October 2006 | Norway | | | | Bauwens |

| | Date | - , | | | | | 5 K I | |
|---------------|--------------|-------------------|--|----------------------|---------------|--------------------------------|-------------------|----------------|
| Domain | (mm/ yy)? | Type of activity? | More information | Where? | Result: what? | More information | Result: how much? | Who? |
| Domain | 77/- | activity. | More information | where. | nesult. What. | More imormation | applied | WIIO. |
| | | | | | | | budgets for | |
| | | | | | | | IF: 2007: | |
| | | | | | | | 219.755€- | |
| | | | | | | | 2008: | |
| | | | | | | | 219.755€ | |
| | | | application NORAD for 2007- | Brussels, | | | -2009:219.7 | |
| IF DC | 06/06 | Application | 2009 | Belgium | Other | | 55€ | |
| | | | project visit Kijabe and | | | | | |
| IE D.C | 07/06 | | preparation conference May | Kenya and | | | | |
| IF DC | 07/06 | Visit | 2007 | Uganda | | | , | |
| | | | Meeting with Eric Weerts | Donosala | | | | |
| IF DC | 00/06 | Maatina | (Handicap International), | Brussels, | Cooperation | | | |
| IF DC | 08/06 | Meeting | preparation contacts in Vietnam Meeting with Nel Van Manen | Belgium Den Besch | Cooperation | | | Lieven Bauwens |
| | | | and Bernard Morvan, Liliane | Den Bosch, the | | LE and IE have requier | | and Pierre |
| IF DC | 00/06 | Meeting | Foundations | Netherlands | Cooperation | LF and IF have regular contact | | Mertens |
| IF DC | 06/00 | Meeting | Foundations | Brussels, | Cooperation | CONTACT | | Merteris |
| IF DC | 09/06 | Other | half yearly report for SHIA | Belgium | Report | | | Els De Clercq |
| 11 00 | 03/00 | Otrici | Meeting with B Braun, Myleen | Deigiani | пероп | | | LIS De Cicieq |
| | | | Christiaens on B Braun | | | | | |
| | | | supporting the bowel | Leuven, | | | | |
| IF DC | 09/06 | Meeting | management workshop | Belgium | Contact | | | |
| | | | | | , | + | trained | |
| | | | | | | | professional | |
| | | | | | | | s: 19 from 5 | |
| | | | | | | | countries (7 | |
| | | | | | | | projects) | |
| | | | | | | training by Dr Carla | direct | |
| | | | | | | Verpoorten and Myleen | trained | |
| IF as Network | 10/06 | Training | bowel management training | Kijabe, Kenya | Other | Christiaens | parents: 6 | |

| | Date (mm/ | Type of | | | | | Result: how | |
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| Domain | (mm/ yy)? | Type of activity? | More information | Where? | Result: what? | More information | much? | Who? |
| | | | Meeting with Peter van Acker, | , | | | | |
| | | | secretary Development | | | | | |
| IE D.C | 10/06 | | Cooperation Belgian Embassy | Kampala, | . | Important for recognition | | |
| IF DC | 10/06 | Meeting | Uganda | Uganda | Contact | as ngo | | |
| | | | Meeting with Dr Borgstein of | Duvasala | | | | |
| IF DC | 10/06 | Meeting | the Malawi project (with Els, Lieven and Pierre) | Brussels, Belgium | | | | |
| ii bc | 10/00 | Meeting | Lieverrand Flerre) | beigium | | Visit of 4 different hotels | | |
| | | | | | | and conference centres | | |
| | | | Prospect tour Kampala for the | Kampala, | | (with and without Aloysius | | |
| IF DC | 10/06 | Other | conference | Uganda | | Bakkidde) | | |
| | | | | Uganda and | , | evaluation by Eva Naess | | |
| IF DC | 10/06 | Evaluation | external evaluation for NORAD | Kenya | Report | and Carla Verpoorten | | |
| | | | | | | | open | |
| | | | | | | | debate with | |
| | | | | | | | manageme | |
| IE DC | 10/06 | Maatina | | Viiaha Vanua | | | nt from 6 | |
| IF DC | 10/06 | Meeting | project management meeting | Kijabe, Kenya | -1 | | projects official | |
| | | | | | | | contact with | |
| | | | workshop IDDC on UN | | | | DSI rep (for | |
| | | | convention: implementation in | Brussels, | | networking with other | DANIDA | |
| IF DC | 11/06 | Meeting | the South | Belgium | Other | NGO's | support) | |
| | , | | | | | | other | |
| | | | | | | | members to | |
| | | | | | | | Vietnam IF | |
| | | | follow up sponsor opportunities | Italy – IF | | | activities in | |
| IF DC | 11/06 | Other | members for IF projects (Italy) | office | Cooperation | ongoing | South | |
| | | | | | | | guidelines | |
| | | | | | | | for | |
| | | | support Vietnam guidelines | D ' | | ongoing – in cooperation | supporting | |
| IE DC | 11/0- | Ouls | "how to guide a parent group | Brussels, | Other | with Eli Skattebu and Joyse | groups in | |
| IF DC | 11/06 | Other | towards independence" for DC | Belgium | Other | Mallya (Moshi) | Africa | |

| Domain | Date (mm/ yy)? | Type of activity? | More information | Where? | Result: what? | More information | Result: how much? | Who? |
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| IF DC | | Negotiation | negotiate with Danish organisation to develop project towards DANIDA in cooperation | | Cooperation | ongoing | aim is to develop new project + funds for project | Wild. |
| IF DC | 11/06 | Other | prepare revision WHO manual on SB in DC – contact with WHO – contact with projects to prepare | Brussels, Belgium | Publication | ongoing | will result in re-edited version of WHO manual | |
| IF DC | | Meeting | New country strategy for Tanzania presented at meeting on 22 November all afternoon in SHIA's office, after renewed directives from SIDA, the Swedish agency for support to developing countries. | Stockholm, Sweden | | | | Renée took part |
| IF DC | 12/06 | Evaluation | prepare project reporting 2006 activities and results | Brussels, Belgium | Report | | | · |
| IF DC | 12/06 | Other | follow up contacts STORZ | Brussels, Belgium | Other | ongoing | Silver book | |
| IF DC IF DC | | Training Other | prepare meeting to develop training packages CIC and bowel management contact authors of Incidence survey study | Brussels, Belgium Brussels, Belgium | Other Cooperation | ongoing ongoing | training packages CIC and bowel manageme nt for projects we hope to start incidence | |
| | | , | | | | | study in Vietnam | |

| | Date (mm/ | Type of | | | | | Result: how | |
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| 201114111 | 777 | <u>udurity</u> | | | 1105010 111100 | more innormation | | |
| | | | | | | | | |
| | | | | | | | country | |
| | | | | | | | training | |
| | | | | | | | shunting and ETV in | |
| | | | | | | | Vietnam, | |
| | | | preparation training Vietnam | Brussels, | | | expansion | |
| IF DC | 12/06 | Training | (march 2007) | Belgium | Cooperation | | knowledge | |
| | | | | | | | | Eva Toft, Karin |
| | | | | | | | | Berggren, Liiso |
| | | | | | | | | Akerberg, |
| | | | | Moshi + Dar | | | | Renée Höglin, Gunilla |
| | | | 9-18 December: evaluation + | es Salaam, | | | | Boëthius, Pierre |
| IF DC | 12/06 | Evaluation | visit – see separate report | Tanzania | | | | Mertens. |
| | ,, | | · · · · · · · · · · · · · · · · · · · | | | | network of | |
| | ongoi | | follow up all contacts and | Brussels, | | | contacts in | |
| IF DC | ng | Other | requests from South | Belgium | Contact | | South | |
| | ongoi | | follow up fundraising and | | | Broeders van Liefde - | | |
| IF DC | ng | Fundraising | cooperation opportunities | IF office | Cooperation | World bank | | Els de clercq |
| | | | | | | Kathy Sinnott wants to | | |
| | | | | | | collaborate with IF on this matter and also provided | | |
| | | | Discussed with Irish MEP Kathy | | | contact with Dutch MEPs | | |
| | | | Sinnott about Groningen | Brussels, | | Mr. Blokland and Mr. Belder | | |
| IF HR | 01/06 | Meeting | Protocol | Belgium | Cooperation | (ChristenUnie/SGP) | | Pia Wurzer |
| | | | Following Belgian media | J | | | | |
| | | | attention to the Dutch | | | | | |
| | | | Groningen Protocol, IF | | | | | Pierre Mertens, |
| .== | 24/5- | | discussed the matter with | Brussels, | | | | Pia Wurzer and |
| IF HR | 01/06 | Meeting | Cardinal Danneels | Belgium | Contact | | | Lieven Bauwens |

| | Date (mm/ | Type of | | | | | Result: how | |
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| | 00/04 | Speech / | | India, | | | | 5. |
| IF HR | 02/06 | lecture | presentation on ethics | Mumbai | Contact | · | | Pierre Mertens |
| | | | l. D. M. | | | Following article in Il Foglio | | |
| | | | Interview Pierre Mertens in | | | IF was contacted by the | | |
| | | | Italian newspaper II Foglio "With Dutch active termination of life, | | | Italian paediatrician Clementina Isimbaldi | | |
| | | | all newborn children with Spina | | | (Medicina e Persona) to | | |
| IF HR | 03/06 | Other | Bifida are at risk" | Milan, Italy | Cooperation | collaborate with IF | | Pierre Mertens |
| | 03/00 | Other | European Biopolitics | willari, italy | Соорстаноп | Conaborate within | , | TICITE MICHELLS |
| | | | Conference "Connecting Civil | | | German MEP Hiltrud Breyer | | |
| | | | Society - Implementing Basic | Berlin, | | (Bioethics Intergroup of the | | |
| IF HR | 03/06 | Meeting | Values" | Germany | Contact | EP) | | Pierre Mertens |
| | | | Article Pierre in Belgian | | | | | |
| | | | newspaper De Standaard "Does | | | | | |
| | | | Spina Bifida have to be made | Brussels, | | | | |
| IF HR | 04/06 | Other | sexier?" | Belgium | Publication | | | Pierre Mertens |
| | | | Invitation from Jana Tutkova | | | | | |
| | | | (European Policy Officer CORE) | | | | | |
| | | | to "Hands Off our Ovaries" | | | | | |
| | | | presentation at the EP facilitated by MEP Anna | | | | | |
| | | | Zaborska (Chairwoman of EP | | | | | |
| | | | Committee on Women's Rights), | | | | | |
| | | | Italian MEP Patrizia Toia and | | | Discussed Groningen | | |
| | | | Irish MEP Kathy Sinnott. | | | Protocol with assistant MEP | | |
| | | | Presentation of two books of | | | (Belder/Blokland) Frank | | |
| | | | feminist authors. Italian book: | | | van der Maas. IF can | | |
| | | | "Madri selvagge" by Alessandra | | | contact Mr. Jan Wijmenga | | |
| | | | di Pietro and Paola Tavella and | | | (officer Environment and | | |
| | | | Irish book "Pink girl" by Isla | Brussels, | | Health) for further | | |
| IF HR | 05/06 | Visit | McGuckin | Belgium | Cooperation | collaboration | | |

| | Date (mm/ | Type of | | | | | Result: how | |
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| Domain | yy)? | activity? | More information | Where? | Result: what? | More information | much? | Who? |
| | | C | IF presented Resolution on the | | | EDE Decelotion on the | | |
| IETID | 05/06 | Speech / | Right to Live at EDF Annual | Dama Italy | Decelution | EDF Resolution on the | | Diagra Magtaga |
| IF HR | 05/06 | lecture | General Assembly 27-28 May 06 | Rome, Italy | Resolution | Right to Live | | Pierre Mertens |
| | | | IF Policy Statement on the Right to Live presented at IF's Annual | | | | | Pierre Mertens |
| | | | | Helsinki, | | | | and Lieven |
| IF HR | 06/06 | Othor | General Meeting 29 June - 2 July | Finland | Resolution | | | Bauwens |
| ІГ ПК | 06/06 | Other | Clementina Isimbaldi and Paolo | rinianu | Resolution | Diama is invited to present | | Dauwens |
| | | | | | | Pierre is invited to present | | |
| IF HR | 07/06 | Mostina | Arosio, Italian paediatricians | Tuccopy Italy | Cooperation | his book <i>Liesje</i> at Medicina e Persona in October 06 | | Pierre Mertens |
| IF FIR | 07/06 | Meeting | (Medicina e Persona) | Tuscany, Italy | Cooperation | e Persona in October 06 | | Slovakian |
| IF HR | 00/06 | Translation | Liasia translated in Clavakian | | Publication | | | |
| IF FIN | 06/00 | Translation | Liesje translated in Slovakian | | Publication | -Interview with Pierre in | | organsation |
| | | | | | | Italian newspaper Avvenire | | |
| | | | | | | (22/10/06) "Nessuna | | |
| | | | | | | giustificazione per | | |
| | | | | | | l'eutanasia dei bimbi" ["No | Another | |
| | | | | | | giustification for active | meeting is | |
| | | | | | | termination of life on | organised in | |
| | | | | | | children"]. Translation | Rome (Feb | |
| | | | | | | available in Dutch. | 07) and | |
| | | | | | | Interview with Pierre at | Medicina e | |
| | | | | | | Telelombardia -Clementina | Persona | |
| | | | | | | Isimbaldi wrote article for | again | |
| | | | | | | Italian newspaper Libero | invited | |
| | | | | | | (to be published). | Pierre to | |
| | | Speech/ | | | | Translation available in | present his | |
| IF HR | 10/06 | lecture | About <i>Liesje</i> | Milan, Italy | Publication | English. | book Liesje | Pierre Mertens |
| | , | | Interview with Pierre in the TV | | | | | |
| | | | programme "Recht van | Brussels, | | | | |
| IF HR | 11/06 | Other | Antwoord" | Belgium | Other | ?? | | Pierre Mertens |

| Domain | Date (mm/ yy)? | Type of activity? | More information | Where? | Result: what? | More information | Result: how much? | Who? |
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| | | Press | Following discussion in Belgian | | | | | |
| IE LID | 11/06 | release / | newspaper De Standaard, IF did | Brussels, | Other | | | |
| IF HR | 11/06 | press action | a press release | Belgium | Other | To most IF were butters are LINI | | |
| | | | | | | To put IF resolution on UN | | |
| | | | | | | agenda: - Simon Walker (Advisor Human Rights and | | |
| | | | | | | Disability-Office of the | | |
| | | | | | | High Commissioner for | | |
| | | | | | | Human Rights) - Vittoria | | |
| | | | | | | Beria (UN Secretariat for | | |
| | | | Concerning how to implement | | | the Convention on the | | |
| | | | UN Disability Convention in | Brussels, | | Rights of Persons with | | |
| IF HR | 11/06 | Meeting | Development countries | Belgium | Contact | Disabilities) | | |
| | | | | | | Mrs. Maria Veronica Reina | | |
| | | | | | | (International Disability | | |
| | | | | | | Caucus) participation in the | | |
| | | | IF sent resolution on the Right | | | implementation of the UN | | |
| IF HR | 12/06 | Other | to Live to Vittoria Beria | USA | Contact | Disability Convention | | Pia Wurzer |
| | | | | | | | | |
| | | | Lecture "Je zal niet doden" | | | | | |
| | | Cooodb / | ["You shall not kill"] at study day | A 10 to 1 10 110 | | | | |
| IF HR | 12/06 | Speech / lecture | organised by UCSIA and University of Antwerp | Antwerp, | Publication | The Dialogue Series/9 | | Pierre Mertens |
| IL UV | 12/00 | iecture | Offiversity of Antwerp | Belgium | FUDIICALIOIT | Special Rapporteur on the | | riene mertens |
| | | | | | | Right to Health: Mrs. | | |
| | | | | | | Dragana Korljan - Special | | |
| | | | | | | Rapporteur on Disability: | | |
| | | | IF sent resolution on the Right | | | Mrs. Sheikha Hessa Al- | | |
| IF HR | 12/06 | Other | to Live to Simon Walker | Switzerland | Contact | Thani | | Pia Wurzer |

| Domain | Date (mm/ yy)? | Type of activity? | More information | Where? | Result: what? | More information | Result: how much? | Who? |
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| | | , | Reaction from Pierre to Veerle Beel (Belgian newspaper De Standaard) following their publication of the story of Inge | | | Interview with Pierre in Belgian newspaper De Standaard "Do not eliminate children with SB | | |
| | | | Verhelst "My child just wanted | Brussels, | | with an hypodermic | | |
| IF HR | 12/06 | Other | to die" | Belgium | Publication | needle" 11/12/06 | | Perre Mertens |
| IF KN | 03/06 | Meeting | Meeting with Bert Schodts, Internet specialist | Leuven, Brussels | | | | Lieven Bauwens |
| IF KN | 04/06 | Conference | One-day-conference in Stockholm about Spina Bifida and Hydrocephalus in adults for leading medical and psycho- social experts on SB&H | Stockholm, Sweden | | | | Presentation by Renée Höglin and Mattias (son) |
| IF KN | 04/06 | Conference | conference on Transition from teens to adulthood for individuals with impairments in Toronto, Canada, 9-18 April. | Toronto, Canada | | | | Renée Höglin |
| IF KN | 06/06 | Conference | Preparations for a full two-day- conference on Spina Bifida and Hydrocephalus to be held in Linköping, Sweden | Sweden | | | | <u> </u> |
| IF KN | | Other | Development IF Knowledge Network - first version | Belgium | Other | Website: http://83.101.18.238/ | Outsourced to Limpid Studios | |
| IF KN | 08/06 | Training | Development of user/administrator handbook of the IF Knowledge Network | Belgium | Publication | User manual IF Knowledge Network | | Miek Van den Stock |
| .= | 00/5- | - | Scientific conference on | Gothenburg, | | | | |
| IF KN | | Conference | Hydrocephalus | Sweden | | , | 450 | <u> </u> |
| IF KN | 10/06 | Conference | A full two-day-conference on Spina Bifida and Hydrocephalus to be held in Linköping late | Linköping, Sweden | | | 150 participants including | Project group: Eva Toft, Karin Berggren and |

| | Date | | | | | | | |
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| Domain | (mm/ yy)? | Type of activity? | More information | Where? | Result: what? | More information | Result: how much? | Who? |
| Domain | yy): | activity: | More information | where: | nesuit. Wilat: | More information | individuals with Spina Bifida, parents, | WIIO: |
| | | | | | | | siblings, professional | |
| | | | | | | | s, plus 25 | |
| | | | autumn. | | , | - | lecturers. | Renée Höglin |
| | | | Discussed with Irish MEP Liam Aylward the possibility to amend the draft EU regulation | | | | | |
| | | | on the (voluntary) addition of | | | Wants to research the | | |
| | | | vitamins and minerals to foods making the addition of folic acid | Brussols | | matter further and wants to get an idea of the | | Pia Wurzer and |
| IF PR | 01/06 | Meeting | mandatory | Belgium | Contact | opinions of other MEPs | | Lorraine Leeson |
| | | | IF sent activities report on prevention to UN Standing Committee on Nutrition, | | | | | |
| | | | Working Group on | | | IF is mentioned in UN | | |
| IF PR | 01/06 | Other | Micronutrients | USA | Report | report | | Pia Wurzer |
| | | | Discussed with Irish MEP Kathy | | | Very supportive for voluntary fortification 'with active encouragement', but against mandatory for concerns of mass medication. Public must have choice to decide. | | |
| | | | Sinnott the possibility to amend the draft EU regulation on the (voluntary) addition of vitamins | | | Some countries (eg NL, some Scandinavian countries) have | | |
| | | | and minerals to foods making | | | constitutional clauses very | | |
| IE DD | 01/06 | Mosting | the addition of folic acid | Brussels, | Contact | reluctant to such | | Pia Wurzer and |
| IF PR | 01/06 | Meeting | mandatory | Belgium | Contact | processes. | | Lorraine Leeson |

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| Domain | yy)? | activity? | More information | Where? | Result: what? | More information | much? | Who? |
| | | | | | | At second reading it would | | |
| | | | | | | not be possible to | | |
| | | | | | | introduce new ideas. EU would not have the legal | | |
| | | | | | | power to introduce | | |
| | | | Discussed with English MEP | | | mandatory fortification, as | | |
| | | | Linda McAvan the possibility to | | | it would fall under Public | | |
| | | | amend the draft EU regulation | | | Health, generally a national | | |
| | | | on the (voluntary) addition of | | | issue (subsidiarity | | |
| | | | vitamins and minerals to foods making the addition of folic acid | Prussols | | principle). The current regulation is about Internal | | Pia Wurzer and |
| IF PR | 01/06 | Meeting | mandatory | Belgium | Contact | Market. | | Lorraine Leeson |
| | 01/00 | Meeting | IF sent activities report to FFI | Deigiani | Correct | Market | | Lonaine Leeson |
| IF PR | 01/06 | Other | Leaders Group | USA | Report | Is not ready yet | | |
| | | | | | | Happy to support IF's call | | |
| | | | Discussed with Irish MEP Avril | | | on mandatory food | | |
| | | | Doyle the possibility to amend the draft EU regulation on the | | | fortification - need to meet up with John Bowis, who | | |
| | | | (voluntary) addition of vitamins | | | would be in the position to | | |
| | | | and minerals to foods making | | | call for a EPP group | | |
| | | | the addition of folic acid | Brussels, | | amendment - technical | | Pia Wurzer and |
| IF PR | 01/06 | Meeting | mandatory | Belgium | Cooperation | questions. | | Lorraine Leeson |
| | | | Two meetings "Flour | | | | | |
| | | | fortification in Vietnam: an | | | | | |
| | | | opportunity for prevention of nutritional deficiency anaemia | | | | | |
| | | Support | and neural tube defect" 10-14 | | | | | |
| IF PR | 02/06 | letter | February 06 | Vietnam | Contact | | | Pia Wurzer |
| | | | • | Mumbai, | | | | |
| IF PR | 02/06 | Meeting | opening meeting FF initiative | India | Cooperation | | | Pierre Mertens |
| | | C | First National Update on Spina | N.4 | | | | |
| IF PR | 02/06 | Speech / lecture | Bifida and Hydrocephalus Conference | Mumbai, India | Publication | | | Pierre Mertens |
| 11 F IX | 02/00 | iectule | Contractice | iriuia | rublication | | | i iei ie iviei tei is |

| | Date (mm/ Type of | | | | | Result: how | |
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| | | Dr. Le Thi Hop, National Institute of Nutrition (NIN) | Ho Chi Minh | | - IF promised to provide information on how to do a survey on the incidence of Spina Bifida so that a survey can be done on the incidence of NTD's in India - IF will examine the possibilities to fortify also other products than flour | | Pierre Mertens and Carla |
| IF PR | 02/06 Meeting | Deputy Director | city, Vietnam | Cooperation | eg. fish salt sauce | | Verpoorten |
| | | Discussed with English MEP John Bowis the possibility to amend the draft EU regulation | | | Mandatory fortification cannot happen at EU level because of all the reasons mentioned before. First individual EU countries should implement it. Willing to collaborate on: - disseminating information | | |
| IF PR | 03/06 Meeting | on the (voluntary) addition of vitamins and minerals to foods making the addition of folic acid mandatory | Brussels, Belgium | Contact | and raising awareness about folic acid - mapping health problems and how they are being met | | Pia Wurzer, Lorraine Leeson and Lieven Bauwens |

| | Date | | | | | | | |
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| Domain | yy)? | activity? | More information | Where? | Result: what? | More information | much? | Who? |
| | | | Discussed with Mr. Philippe | | | Mandatory fortification | | |
| | | | Brunet (Head of Cabinet DG | | | cannot happen at EU level | | |
| | | | SANCO) and with Mr. Fabio | | | because of all the reasons | | |
| | | | D'Atri (DG Health and | | | mentioned before. | | |
| | | | Consumer Protection, Unit E4 | | | Importance of taking | | |
| | | | "Food Law, Nutrition and | | | supplements should be | | |
| | | | Labelling") the possibility of a | | | promoted. Willing to collaborate on: - | | |
| | | | European regulation on mandatory flour fortification | | | | | |
| | | | with folic acid following the | | | disseminating information and raising awareness | | Pia Wurzer, |
| | | | draft EU regulation on the | | | about folic acid - mapping | | Lorraine Leeson |
| | | | (voluntary) addition of vitamins | Brussels, | | health problems and how | | and Lieven |
| IF PR | 03/06 | Meeting | and minerals to foods | Belgium | Contact | they are being met | | Bauwens |
| | 03/00 | weening | and minerals to roods | Deigiani | contact | Presentation of his paper | | Budweils |
| | | | | | | on prevention of Spina | | |
| | | | | | | Bifida . He asked for IF's | | |
| | | | Teleconference with Mr. | Washington | | support if he proposes it to | | |
| IF PR | 04/06 | Meeting | Godfrey Oakley | DC, USA | Contact | the Bill Gates Foundation | | Lieven Bauwens |
| | | Support | Science and Milling Conference | | - | | | |
| IF PR | 05/06 | | on Flour and Food Fortification | Vietnam | Contact | | | |
| | ' | | | | , | Letter of support to | | |
| | | | | | | support meeting of bakers | | |
| | | | | | | in China, as the meeting | | |
| | | Support | | Shanghai, | | was about fortification of | | |
| IF PR | 05/06 | letter | Bakery China 17-19 May 06 | China | Contact | flour | | |
| | | | | | | EDSA will support IF | | |
| | | | | | | actions regarding folic acid | | Pierre Mertens |
| | | | European Down's Syndrome | | _ | and mandatory | | and Lieven |
| IF PR | 05/06 | Meeting | Association (EDSA) | Rome, Italy | Cooperation | fortification | | Bauwens |

| | Date | T of | | | | | Do avelée la com | |
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| Domain | (mm/ yy)? | Type of activity? | More information | Where? | Result: what? | More information | Result: how much? | Who? |
| Domain | 77/ | activity. | FFI High Level Meeting 10/11 | where. | nesure. What. | More information | macii. | W110. |
| | | | May "Addressing Vitamin and | | | | | |
| | | | Mineral Deficiency Damage to | | | | | |
| | | | the People of the People's | | | | | |
| | | Speech/ | Republic China: Mandatory | Beijing, | | | | |
| IF PR | 05/06 | lecture | Fortification of Wheat Flour" | China | Cooperation | | | Pierre Mertens |
| | | Support | Interbake China 2006 trade | Guanghzhou | | | | |
| IF PR | 05/06 | letter | show 12-14 May 06 | , China | Contact | | | Pia Wurzer |
| | | | Supported FSANZ regarding the | | | | | |
| | | | benefit of mandatory flour | | | | | |
| | | | fortification with folic acid in | | | | | |
| | | | order to achieve mandatory | ь . | | | | D: 14/ |
| IF PR | 07/06 | Support | fortification with folic acid in | Brussels, | Otla au | | | Pia Wurzer and |
| IF PK | 07/06 | letter | Australia/NZ | Belgium | Other | Duet Diegenele | | Lieven Bauwens |
| | | | GASBI's national conference on | | | Prof. Pierpaolo Mastroiacovo (ICBD) - Dr. | | |
| | | | prevention "Clinical and | | | Giorgio Lorenzo Colombo | | |
| | | | economical impact of Spina | | | (SAVE/Rotary) - Dr. Adriano | | |
| | | Speech/ | Bifida in Italy: the value of | | | Ferrari (Modena and | | |
| IF PR | 09/06 | lecture | prevention" | Milan, Italy | Cooperation | Reggio Emilia University) | | Pierre Mertens |
| | | | , 12 - 2 - 2 - 2 - 2 | , , , , , | ! | IF will most of the times be | 1 | |
| IF PR | 10/06 | Application | Network Italiano Acido Folico | Rome, Italy | Membership | represented by GASBI | | Pia Wurzer |
| | | | Australia/NZ commit to | | | | | |
| | | Press | implement mandatory | | | | | |
| | | release / | fortification of bread with folic | | | | | |
| IF PR | 10/06 | press action | acid | | Other | | | |
| | | | FFI Leader Group Meeting in | | | Collaboration with Flour | | |
| | | | Turkey to bring about | | | Fortification Initiative (FFI) | | |
| | | Support | mandatory flour fortification in | Istanbul, | _ | Collaboration with Turkish | | |
| IF PR | 11/06 | letter | the Eurasia region 12/13 Nov 06 | Turkey | Cooperation | SB/H organization | | Pia Wurzer |

Activity report Development Cooperation

General aim and goals of the programme:

A better life situation for people with Spina Bifida and Hydrocephalus in the project countries through support of local based rehabilitation programmes and the support of parent groups:

- × To improve the basic treatment of children with Spina Bifida and Hydrocephalus through the training of professionals at all levels within the local health service and parents.
- × To establish parent groups in all project countries to subsequently build organisations.
- × To work for the inclusion of children with Spina Bifida and their families in society.
- × To increase our knowledge of diagnoses and their treatment through research

Shunts in 2006

| Ivory Coast | 10/01/2006 | 20 |
|--------------------------------|------------|------|
| Benin | 23/01/2006 | 20 |
| Zambia | 16/02/2006 | 250 |
| Philippines-Congo | 27/02/2006 | 50 |
| Senegal | 1/03/2006 | 10 |
| Vietnam | 6/03/2006 | 5 |
| Dominican Republic | 22/03/2006 | 10 |
| Ethiopia | 5/04/2006 | 20 |
| Cameroon | 28/04/2006 | 20 |
| Zimbabwe | 28/04/2006 | 10 |
| Bolivia | 4/05/2006 | 30 |
| Ecuador | 27/07/2006 | 20 |
| Ethiopia | 2/08/2006 | 20 |
| Haiti | 9/08/2006 | 20 |
| IF office (among others China, | | |
| Vietnam) | 9/08/2006 | 75 |
| Gambia | 14/08/2006 | 10 |
| Nigeria | 28/08/2006 | 20 |
| Kenya | 31/08/2006 | 300 |
| Ivory Coast | 18/10/2006 | 20 |
| Senegal | 18/10/2006 | 20 |
| Zimbabwe | 18/10/2006 | 20 |
| Uganda | 25/10/2006 | 140 |
| Angola | 6/11/2006 | 10 |
| Benin | 17/11/2006 | 20 |
| Peru | 3/12/2006 | 10 |
| Ghana | 17/12/2006 | 10 |
| IF projects | 22/12/2006 | 1330 |
| Yemen | 22/12/2006 | 20 |
| | Totaal | 2510 |

Summary of the results

| Country | Tanzania | Tanzania | Kenya | Uganda | Uganda | Malawi | Sudan | Zambia | Other | |
|--|---|--|--|--|--|---|---|---|--|----------------------|
| City | Dar es Salaam | Moshi | Kijabe | Mbale | Katalemwa | Blantyre | Khartoum | Lusaka | Various | Total |
| Exact name of the partner | CCBRT disability hospital | CCBRT Kilimanjaro in cooperation with / KCMC Moshi | Bethany Kids at Kijabe Hospital | Cure Children's hospital of Mbale | Katalemwa Cheshire Home for Rehabilitatio n Services | Department of Surgery, College of Medicine | Cheshire Home Khartoum | Cheshire Home Lusaka | Handicap International Liliaene Fonds | |
| Contact person | Richard Hess Geert Vanneste | Joyse Mallya Geert Vanneste | Dr Richard Bransford Dr Dan Poenaru | Charles Howard | Aloysius Bakkidde | Prof Eric Borgstein | Edith Christine | Eckhard Kern Margriet Kern- Heddema | | |
| Number of shunt operations | 154 of which 40 ETV's | 31 | 391 | 466 of which 284 ETV's | | 433 | | 302 | Preparation ETV training | 1777 (324 ETV) |
| Number of Spina Bifida operations | 83 | 4 | 195 | 99 | | 4 | | | | 385 |
| Number of children in CIC - follow-up | 119 | 52 | 101 | 104 | 78 | 11 | 61 | | Introduction CIC in spinal cord injury project HI | 526 |
| Local personnel paid by the project | Paediatricia n 2 Spina Bifida nurses | top up paediatricia n top up Spina Bifida nurse | 4 Neuro nurses | 1 Spina Bifida nurse 3 social workers 1 research assistant | Social worker | 1 Spina Bifida nurse 4 clinical officers | 1 Spina Bifida nurse 1 Project coordinator | Small top up clinical officer | n/a | |
| Parent meetings | 1 | 7 | 31 local group meetings | | 3 | 2 | 9 | 3 | n/a | 56 |

| Average Attendance of parent meetings | 80 | 22 | Not reported | | 46 | 100 | 30 | 21 | n/a | |
|--|-----------------|-----------------|-----------------|-------------|-------------|-----|----|----|---|--|
| Project visit | December '06 | December '06 | October '06 | October '06 | October '06 | | | | India / Vietnam: March '06 China: May '06 Meeting LF August '06 | |

All projects were represented in the annual African workshop, held 17-20 October 2006 in Kijabe, Kenya.

IF Award 2006

During the opening session of the 2006 International Conference in Helsinki, Finland, IF awarded its annual IF award to Mr Bo Hjelt. Mr Hjelt, a father to three children with Spina Bifida, has dedicated his life and the resources of his foundation to research into the real causes of Spina Bifida. He received the IF award, a statue by Pierre Mertens, in the country that has nominated him as IF board member during 8 years.



Before planting the seeds, people should be advised to take folic acid.

Mr Hjelt is one of those devoted individuals in the IF network who made a real difference in the research on the real causes of neural tube defects. Bo Hjelt is a businessman who was confronted with 3 children with Spina Bifida. He decided to invest in research by creating the CDI foundation, named after his company. This foundation received 2,5% from Bo Hjelt's total worldwide business revenue. Next to the CDI foundation, Mr Hjelt has organised events to raise funds via the Friends of IF.

Pierre Mertens says: "years ago, I contacted Bo and asked him to help IF financially. As it goes when a parent meets another parent, the contact was immediately warm and open. Our first workshop in Africa was sponsored by Bo's private money. He made his complete network available to our organisation, and he accepted to be a member of the IF board for many years. Even today, he is a member of the management committee."

Financial result 2006

Report of the auditor

Report of the statutory auditor on the financial statements for the year ended 31-12-2006 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 31-12-2006, prepared under the responsibility of the board of directors of the federation, which show a balance sheet total of \in 388.859,85 and a profit for the year of \in 11.571,60.

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].

UNQUALIFIED 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 31/12/2006 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, February 21th 2007

(signed)

BVBA De Nul & co bedrijfsrevisor Statutory auditor

Profit and loss 2006

| | COSTS | | | |
|----|------------------------------|-------------|----|---|
| 61 | Diverse costs | 294.842,30€ | 74 | |
| | Rent office | 5.575,55€ | | |
| | Divers rent costs | 5.630,00€ | | |
| | Energy | 795,44€ | | |
| | Office supplies | 1.333,50€ | | |
| | Publications - copy | 2.881,95€ | | |
| | Documentation - books | 58,50€ | | |
| | Public relations/fundraising | 2.224,25€ | | |
| | Website | 376,07€ | | |
| | Telephone - fax - mail | 2.301,48€ | 75 | |
| | Postal costs | 848,06€ | | |
| | Transporters | 2.769,01€ | | |
| | Membership fees | 875,00€ | | |
| | Fee translator | 243,01€ | 76 | |
| | Fee bookkeeper | 2.504,81€ | | ٠ |
| | Fee auditor | 1.724,25€ | | |
| | Fee management consulting | 3.392,00€ | | |
| | Fee social secretary | 866,75€ | | |
| | Fee medical secretary | 113,73€ | | |
| | Other fees | 10.007,91€ | | |
| | Insurance | 290,23€ | | |
| | Transport expenses | 21.887,37€ | | |
| | Official documents (visas) | 514,88€ | | |
| | Representation | 7.493,76€ | | |
| | Medical material projects | 62.934,97€ | | |
| | Salaries in projects | 47.826,32€ | | |
| | Training projects | 1.551,68€ | | |
| | Direct grants | 41.000,00€ | | |
| | Other expenses projects | 56.024,44€ | | |
| | Conferences - meetings | 10.797,38€ | | |
| | 3 | • | | |
| 62 | Salary | 81.865,45€ | | |
| | Gross salary | 55.819,76€ | | |
| | 13th month | 2.055,05€ | | |
| | Holiday fee | 4.616,45€ | | |
| | Transport home-work | 2.489,55€ | | |
| | Fixed sum | 2.293,18€ | | |
| | Social charges | 15.714,10€ | | |
| | Provision holiday fee | -1.491,32€ | | |
| | Insurance personnel | 368,68€ | | |
| 63 | Depreciations | 3.849,96€ | | |
| | Depreciations | 3.849,96€ | | |
| 64 | Diverse taxes | 0,00€ | | |
| 65 | Financial costs | 4.786,66€ | | |
| | Bank charges | 3.748,77€ | | |
| | Payment & change differences | 1.037,89€ | | |
| 66 | Exceptional costs | 818,50€ | | |
| | Eventional costs | 010 50 6 | | |

| 4 | General income | 388.349,87€ |
|---|---|--|
| | Membership fees | 3.540,00€ |
| | Subsidies project Norad * Subsidies project SHIA ** Grants Donations - fundraising Diverse recuperation | 216.713,73 € 46.568,70 € 81.214,06 € 20.291,26 € 20.022,12 € |
| | | |

| 75 | Financial income | 9.384,60€ |
|----|--------------------|-----------|
| | Financial products | 8.533,43€ |
| | Change differences | 851,17€ |

| 76 | Exceptional income | 0,00€ |
|----|---------------------------|-------|
| | Exceptional income | 0.00€ |

^{*} NORAD: Norwegian Development Agency

Exceptional costs 818,50 €

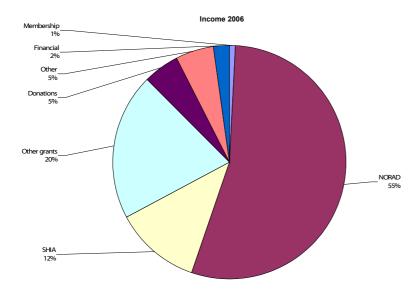
TOTAL COSTS

386.162,87 € TOTAL INCOME RESULT

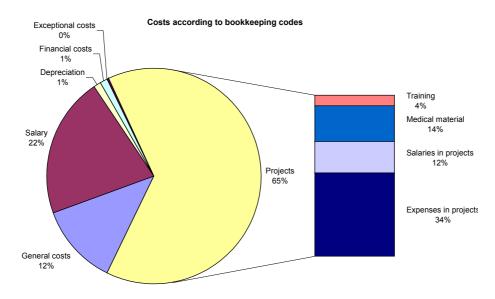
397.734,47 € 11.571,60 €

^{**} SHIA: Swedish Association of Disabled Persons Organisations

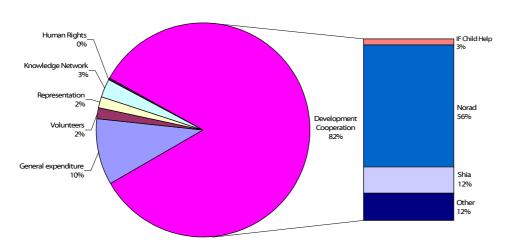
Income 2006



Costs 2006



Analysis of costs



Balance Sheet 2006

| ASSETS | 31-DEC-06 |
|-----------------|------------|
| Tangible assets | 3.098,48€ |
| Investments | 11.548,80€ |
| Depreciations | |
| investments | -8.981,11€ |
| Cautions | 530,79€ |

| Amounts receivable | 22.792,59€ |
|------------------------|------------|
| Customers | 3.018,73€ |
| Advances projects | 6.412,45€ |
| Donations KBS* to | |
| receive | 12.224,07€ |
| Loan IF Child Help vzw | 1.137,34€ |
| | |

| | 361.995,89 |
|----------------------|-------------|
| Bank & cash accounts | € |
| Stocks | 207.626,45€ |
| Bank account | 5.075,81€ |
| Bank savings account | 149.293,63€ |
| | , |

| Transit accounts | 972,89€ |
|---------------------|---------|
| Costs for next year | 972,89€ |

| | 388.859,85 |
|--------------|------------|
| TOTAL ASSETS | € |

| * KBS: King Baudouin Foundation | * KBS: Kina | Baudouin | Foundation |
|---------------------------------|-------------|----------|------------|
|---------------------------------|-------------|----------|------------|

| LIABILITIES | 31-DEC-06 |
|-------------|-------------|
| Reserves | 336.085,13€ |
| Funds of IF | 324.513,53€ |

Profit-los book year 11.571,60€

| Amounts payable | 52.774,72€ |
|---------------------|------------|
| Suppliers | 37.479,06€ |
| Invoices to receive | 2.743,22€ |
| Salary's to be paid | 688,53€ |
| Provision holiday | |
| fee | 9.407,91€ |
| Divers debts (rent) | 2.456,00€ |

| Transit accounts | 0,00€ |
|-----------------------|-------|
| Profits for next year | 0,00€ |

| TOTAL LIABILITIES | 388.859,85€ |
|-------------------|-------------|
|-------------------|-------------|

Staff according to Social Balance 2006

Staff employed during the year: 3

Average FTE: 2,2

Days worked: 406 days

Official (bank) holidays: 15 days

Holidays: 30 days

Maternity / parental leave: 126 days

Legal absence: 1 day

Illness: 5 days

Hours worked: 3083 hours

| IF ivzw International Federation For Spina Bifida and Hydrocephalus Consultative status special category with the Economic and Social Council of the United Nations / Participatory status Council of Europe | |
|--|--|