ANNUAL REPORT 2013

INTERNATIONAL
FEDERATION
for
SPINA BIFIDA
and
HYDROCEPHALUS

Contents

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Created in 1979, the International Federation for Spina Bifida and Hydrocephalus (IF) is the global umbrella organisation for 50 national and regional Spina Bifida and Hydrocephalus (SB-H) organisations.

IF is an International NGO with special category consultative status with the Economic and Social Council of the United Nations. It has also been recognized as one of 7 key EU networks on disability and holds a participatory status at the Council of Europe.

IF's activities are focused on the dissemination of information and expertise throughout the world to families, individuals, professionals and volunteers involved in the field of Hydrocephalus and Spina Bifida.

The mission of the International Federation for Spina Bifida and Hydrocephalus is to improve the quality of life of people with spina bifida and hydrocephalus and to reduce the incidence of neural tube defects and hydrocephalus by primary prevention.

01 We will urge and support national and international agencies and institutions to ensure the full enjoyment of all fundamental human rights of people with spina bifida and hydrocephalus

02 We will form a global network of people and organisations concerned with spina bifida and hydrocephalus

03 We will work to establish a better understanding of the incidence of spina bifida and hydrocephalus and its global impact

04 We will urge and support national and international agencies and institutions to implement best practice in primary prevention

05 We will facilitate, develop and promote the exchange of knowledge, information and good practice

Message from our President

Dear Friends,

It gives me great pleasure to write to you at the end of my first year as President of IF. It is hard to believe that a year has passed so quickly. It has been a busy and very exciting year with IF moving forward in so many ways. I was very fortunate in that I took over the Presidency when IF was in very good shape, having been in the capable hands of Pierre Mertens for the previous 18 years.

One of my first jobs as President was to accompany Pierre on a trip to Beijing to be introduced to the network of people that Pierre had brought together in order to improve the care provided to people affected by SB&H in China. Both Pierre and I had been asked to give presentations about SB&H at a Rehabilitation Conference organised by the China Disabled Persons Federation (CDPF)– the first time that this topic had been included in their programme. Following this we met with representatives from the sub-section for Physical Disability within CDPF and they agreed in principle to create a group within CDPF responsible for providing care and services for people with SB&H. It was with great pleasure that I returned to China in April 2014 for the official launching of this service in Shenyang. Pierre should be congratulated on making this happen.

In April 2014 I also travelled to Boston with our Secretary General, Lieven Bauwens, to participate in a Partner Engagement Meeting with other organisations including Boston Children's Hospital, the Centers for Disease Control and Prevention and a variety of top American Medical Schools to discuss how we can work 'Better Together' to improve care for people with SB&H and promote primary prevention on a worldwide scale. The meeting was hailed a great success with all parties agreeing that working together is the best way forward. A follow-up meeting in Atlanta has already been organised, which Lieven will also attend.

As a result of the hard work of Stefania Pirani, Lieven Bauwens, Jackie Bland, our treasurer and the other members of IF staff we were successful in being awarded a European Programme grant for a further 12 months. This will allow us to organise a variety of workshops and other programmes particularly within our Eastern European members' countries.

Fundraising is always a difficult issue for all of our members and also for IF. The Board has, therefore, discussed a new fundraising strategy which, if successful, will hopefully also help our member organisations who volunteer to host the annual IF Conference.

The current Board of IF is a truly international one, with representatives from Europe, Africa, India and South America. We work well together and at our Board Meeting in Madrid in March 2014 we agreed to revisit the mission statement of IF and develop a strategy for taking things forward in a variety of different ways.

More information about this will be made available at the General Assembly in Buenos Aires and on the IF website over the next few months.

I feel privileged to have been President of IF for the last 12 months with the progress which has been made. I am extremely lucky to have 'inherited' IF at a time when we have dedicated, hard working staff and a supportive Board of directors. I thank them for their help in guiding me through my first year and will look forward to working with them in the year to come. I will also look forward to meeting many more of our members at our General Assembly and in the years ahead.

Margo Whiteford
IF President

Members of the International Federation for Spina Bifida and Hydrocephalus

Algeria Association des malades de Spina Bifida de Mostaganem
Argentina Asociación Para la Espina Bífida e Hidrocefalia (APEBI)
Australia Spina Bifida Association Queensland; Northcott Spina Bifida Group
Austria Spina Bifida und Hydrocephalus Österreich (SB&HÖ)
Belgium Vlaamse Vereniging voor Spina Bifida en Hydrocephalus vzw (VSH)
Bulgaria Spina Bifida Hydrocephalus Bulgaria
Colombia Fundación Sin Barreras, Fundación Mónica Uribe Por Amor
Croatia Udruga osoba i roditelja djece sa spinom bifidom "Aurora"
Denmark Rygmarvsbrokforeningen af 1988
Estonia The Estonian MMC and HC Society
Finland Suomen CP-liitto ry
France Fédération Française des Associations du Spina Bifida (FFASB)
Germany Arbeitsgemeinschaft Spina Bifida und Hydrocephalus e.V. Bundesverband (ASBH)
Greece Hellenic Association for Spina Bifida and Hydrocephalus
Guatemala Asociación Guatemalteca de Espina Bífida (AGEB)
Honduras Fundación Amado Josue
India Spina Bifida Foundation
Ireland Spina Bifida Hydrocephalus Ireland (SBHI)
Italy A.S.B.I. Associazione Spina Bifida Italia
Japan Spina Bifida Association of Japan
Luxembourg Association pour le Spina Bifida a.s.b.l.
Kenya Spina Bifida and Hydrocephalus Association (SHAK)
Lithuania Spina Bifida ir Hidrocefalija asociacija
Mexico Asociación Mexicana de Espina Bifida A.C. (AMEB)
The Netherlands BOSK Work Group Spina Bifida & Hydrocephalus
Nigeria Festus Fajemilo Foundation
Norway Ryggmargsbrokk- og hydrocephalusforeningen
Peru Asociación de Espina Bífida e Hidrocefalia del Perú (ASESBIH)
Poland Fundacja "Spina"; Stowarzyszenie Chorych z Przepukliną Oponowo-Rdzeniową R.P. (ASBP)
Portugal Associação de Spina Bífida e Hidrocefalia de Portugal (ASBIHP)
Romania Asociatia Romana de Spina Bífida e Hidrocefalie (ARSBH)
Russia Association of Spina Bifida and Hydrocephalus of St. Petersburg
Scotland Scottish Spina Bifida Association (SSBA)
Serbia Spina Bifida and Hydrocpehalus association of Serbia
Slovakia Slovenská spoločnosť pre Spina Bifida a/ alebo Hydrocefalus, o. z.
Spain Federación Española de Asociaciones de Espina Bífida e Hidrocefalia (FEBHI); Associació Catalana d'Espina Bífida i Hidrocefalia (ACAEBH); Asociación Madrileña de Espina Bífida e Hidrocefalia (AMEB)
Sudan Spina Bifida Federal Association
Sweden RBU
Switzerland Schweizerische Vereinigung zugunsten von Personen mit Spina Bifida und Hydrocephalus (SBH)
Turkey Türkiye Spina Bifida Derneği
UK SHINE
USA Spina Bifida Association of America (SBAA)

Board of directors

Margo Whiteford, President, Scotland

Jackie Bland, Treasurer, UK
Lumbwe Chiwele, Zambia
Thelma Cloake, Secretary, Ireland
David Diaz Garcia, Spain
Marit Fjellhaug Nylund,Norway
Emine Nurdan Anli, Turkey
Santosh Karmarkar, India (missing from photo)
Elena Zappoli, Argentina

Representation

The International Federation for Spina Bifida and Hydrocephalus holds Special Consultative Status at the Economic and Social Council of the United Nations (renewed in 2011) and Participatory Status at the Council of Europe (renewed in 2014).

Through the PROGRESS programme, IF holds a privileged relationship with the European Commission. Since 2011 Lieven Bauwens represents IF in the Executive Management Team of the Food Fortification Initiative.

Staff members

Brussels office:

- **Lieven Bauwens** - Secretary General
- **Katalijne Van Diest** – Programme Manager International Solidarity
- **Stefania Pirani -** Programme Manager Europe
- **Janina Arsenjeva** - Programme Manager (2014)
- **Renée Jopp** - Information Officer
- **Ewa Kampelmann** - Communications
- **Anna Maarit Paakkulainen** – PA /Administrator
- **Anna Verster** - Senior Advisor, Fortification

International Staff:

- **Femke Bannink** - Senior Advisor/ Researcher, Kampala, Uganda
- **Rebecca Nakkito** - Administrative Assistant. East-Africa, Kampala, Uganda
- **Liu Jiarong** - liaison in Beijing, China
- **Marisol Hernandez** - liaison in Buenos Aires, Argentina

IF volunteers:
Zjuul Devens, Brigid Glennon,
Eric Holdtgrefe, Viviane Lepingle,
Greta Van Seghbroeck, Mol Mertens

IF Consultative team

- Dr. Richard Bransford, general surgeon, MD, FACS
- Dr. Jan Cordonnier and Mrs. Annick, Uytterhaegen - laboratory
- Mrs. Myleen Christiaens, consultant continence management
- Dr. Filippo Ciantia, tropical medicine, Expo 2015
- Mrs. Kordelia Fischer-Borchert, consultant community-based rehabilitation
- Dr. Philippe Gillis, consultant paediatrics and tropical medicine
- Frank De Graeve, communications advice
- Mrs. Helen Healy, consultant life skills and transition
- Mr. Bo Hjelt, consultant fundraising and general management
- Ms. Sofie Van Houtte, user representation
- Prof. Dr. Emmanuel Keirse, user counselling
- Dr. Joe Mulinare, prevention expert, Centers for Disease Control and Prevention
- Dr. Dan Poenaru, medical consultant, paediatric surgeon
- Mr. Koen Sevenants, senior advisor Development Cooperation Asia
- Dr. Carla Verpoorten, medical consultant, neuro-paediatrician
- Prof. Dr. Patrick De Vlieger, anthropology and disability
- Prof. Benjamin C. Warf, medical consultant, paediatric neurosurgeon, ABNS, ABPNS

Partners

The International Federation for Spina Bifida and Hydrocephalus has vastly enlarged its international network. In 2013 IF was supported by the following bodies:

International Institutions

- European Union (EU)
- Council of Europe (CoE)
- The United Nations Children's Fund (UNICEF)
- United Nations Economic and Social Council (UN ECOSOC)
- World Health Organisation (WHO)

International Organisations

- European surveillance of congenital anomalies (EUROCAT)
- Food Fortification Initiative (FFI)
- European Disability Forum (EDF)
- The European Organisation for Rare Diseases (EURORDIS)
- International Disability and Development Consortium (IDDC)
- European Union Agency for Fundamental Rights (FRA)

Other International NGOs

- Liliane Fonds
- Bethany Kids
- CURE International
- Association of Volunteers in International Service (AVSI)
- International Christian development organisation (CBM)
- WHO Partnership for Maternal, Newborn & Child Health (PMNCH)
- Handicap International (HI)

Companies

- Akzo Nobel
- B BRAUN Medical
- Bayer Healthcare
- Bühler
- Surgiwear

Facts and figures on NTDs

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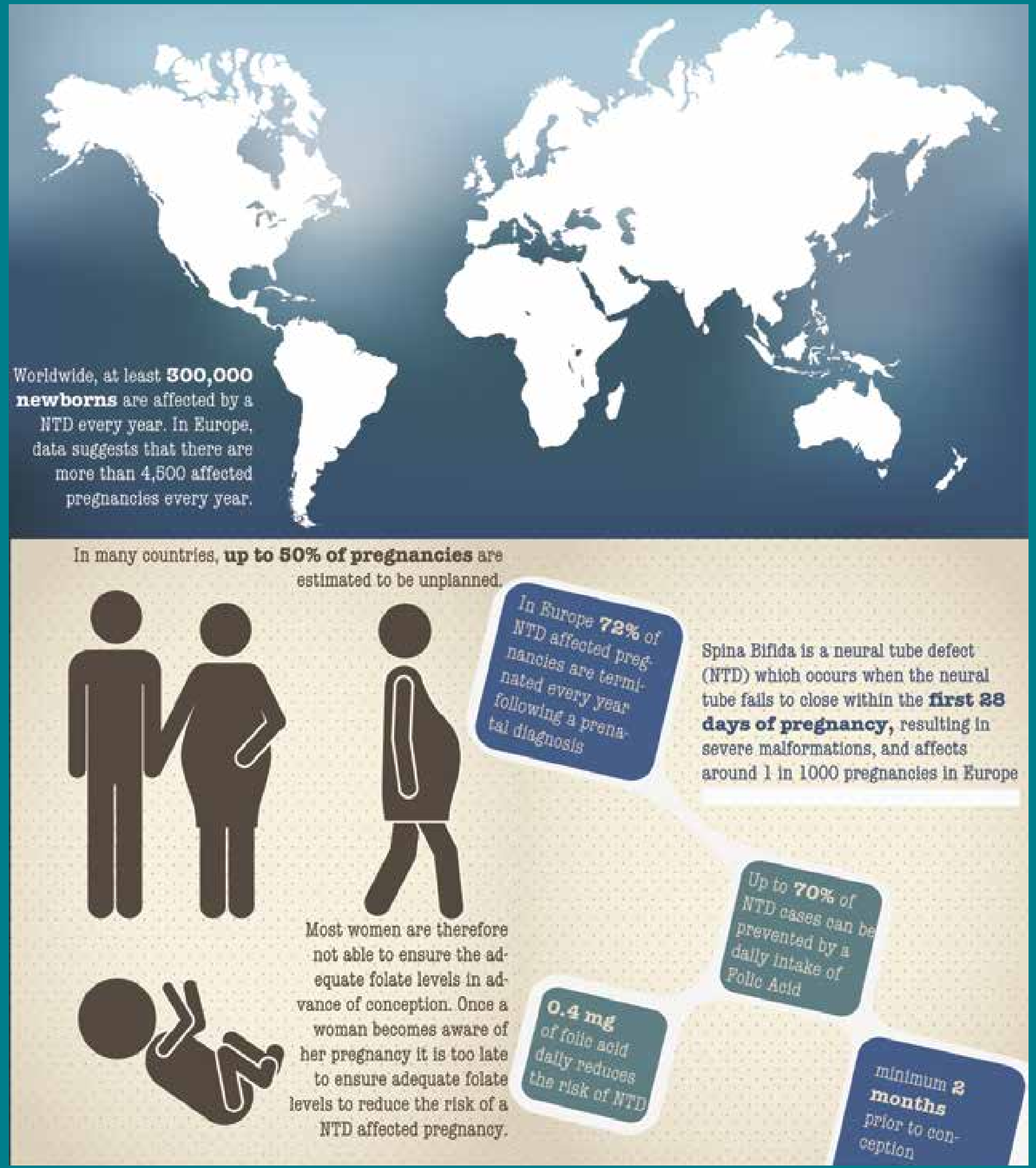
1. Prevention of Neural Tube Defects: Results of the Medical Research Council Vitamin Study. MRC Vitamin Study Research Group. Lancet 1991; 338(8760):131-7
2. Busby A, Armstrong B, Dolk H et al, Preventing Neural Tube Defects in Europe: A Missed Opportunity, Reproductive Toxicology, Vol 20, No 3, pp 393-402, (2005)
3. Ray: BJOG: an International Journal of Obstetrics and Gynaecology May 2004, Vol. 111, pp. 399–408
4. Meijer WM, De Smit DJ, Jurgens RA, De Jong-Van den Berg LTW. Improved periconceptional use of folic acid after patient education in pharmacies: promising results of a pilot study. Int J Pharm Pract 2005; 13:47-51. Ref ID: 14778
5. De Smit DJ, Meijer WM, De Jong-Van den Berg LTW. Foliumzuur voorlichting in de apotheek: bereik van de voorlichting en effecten op kennis over en gebruik van foliumzuur. PW Wetenschappelijk Platform 3[3], 56. 2009.



Worldwide, at least **300,000 newborns** are affected by a NTD every year. In Europe, data suggests that there are more than 4,500 affected pregnancies every year.

In many countries, **up to 50% of pregnancies** are estimated to be unplanned.

In Europe **72%** of NTD affected pregnancies are terminated every year following a prenatal diagnosis

Spina Bifida is a neural tube defect (NTD) which occurs when the neural tube fails to close within the **first 28 days of pregnancy,** resulting in severe malformations, and affects around 1 in 1000 pregnancies in Europe

Most women are therefore not able to ensure the adequate folate levels in advance of conception. Once a woman becomes aware of her pregnancy it is too late to ensure adequate folate levels to reduce the risk of a NTD affected pregnancy.

Up to **70%** of NTD cases can be prevented by a daily intake of Folic Acid

0.4 mg of folic acid daily reduces the risk of NTD

minimum **2 months** prior to conception

PREVENTION

IF at the International "Hidden Hunger" Congress

Hidden Hunger is an increasing problem even in developed countries. Its potentially negative consequences on long-term health are often overlooked and underestimated

[March 2013]
The International Congress "Hidden Hunger - From Assessment to Solutions" took place in Stuttgart, Germany. It was organized by the Food Security Center and the Department of Biological Chemistry and Nutrition at the University of Hohenheim.

The International Congress Hidden Hunger had three objectives:

1. To create awareness of the global problem of hidden hunger.
2. To get scientific issues on the agenda of policy makers, academicians, politicians and industry.
3. To discuss solutions to address the worldwide micronutrient deficiencies.

Margo Whiteford was one of the speakers during the session "Investing in healthy children by increasing folic acid intake". She gave a presentation on neural tube defects. Other topics covered the health significance of folic acid intake, the economical aspects of folic acid fortification of flour, and the myths and beliefs of folic acid use. The session was organized by Sight and Life, in close cooperation with IF, FFI, UNICEF and other stakeholders.

During the four day congress, scientists from different areas, field workers, members of non-governmental organizations and representatives from the administration, management and policy discussed various topics giving Africa and Asia a special attention but also focusing on North America and Europe.

Kosovo begins mandatory flour fortification

Implementation and enforcement of the legislation on flour fortification commenced on 5 April 2013 and the first shipment of premix has arrived to Kosovo

[April 2013]
Legislation with regard to the mandatory fortification of wheat flour with iron and folic acid approved and published in September 2012 made Kosovo the 75th country to require wheat flour fortification with at least iron or folic acid.

FFI and UNICEF organised a training session to increase the capacity of the regulatory authorities, sanitary inspectors, lab technicians, and flour millers, who are responsible for ensuring that flour fortification is conducted in a safe and effective manner. Representatives from Kosovo previously attended a joint FFI/UNICEF workshop in Ankara focusing on quality and process control, legislation standards, monitoring and evaluation. Country teams worked in groups to negotiate details of the monitoring process.

IF represented at the WHO training on surveillance and prevention of birth defects

Prevention of neural tube defects, such as spina bifida, starts before conception. IF promotes primary prevention, as up to 70% of Spina Bifida cases could be prevented by a daily intake of 0.4 mg of Folic Acid two months prior to conception and two months after

[May 2013]
IF's President and Secretary General represented IF at the Training Program on Surveillance and Prevention of Birth Defects and Preterm Birth. The event was organized by the International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR), US Centre for Disease Control and Prevention (CDC) and the World Health Organization (WHO).

The primary goal of the course was to help countries promote primary prevention and the health of children with birth defects by developing and strengthening surveillance activities, developing expertise, building technical capacity, and promoting international cooperation.
In many countries, including developing countries, birth defects and preterm birth are already, or are quickly becoming, the leading causes of childhood death, chronic illness, and disability.

In an effort to address the emerging importance of birth defects, the WHO World Health Assembly on 21 May 2010 adopted a resolution calling all Member States to promote primary prevention and the health of children with birth defects. To achieve these goals, the resolution identified surveillance, capacity building, and international cooperation as key areas for WHO and member countries to promote and strengthen.

The 66th World Health Assembly in Geneva adopted a draft resolution calling for better health care for people with disabilities. Member States are encouraged to ensure that all mainstream health services are inclusive of persons with disabilities; provide more support to informal caregivers, and guarantee the access to services for people with disabilities to help them acquire or restore skills and functional abilities as early as possible.

EU has yet to embrace folic acid fortification of wheat flour

Approximately two thirds of the world population lacks access to fortified wheat flour

[June 2013]
In the EU, an estimated 4500 pregnancies a year are affected by neural tube defects (NTDs) such as spina bifida. Despite the well-documented benefits of flour fortification with folic acid (FA) in the prevention of NTDs and the new evidence that provides a better understanding of purported risks associated with FA, European countries have yet to embrace this cost-effective public health initiative.

IF cooperated on a review article with the Food Fortification Initiative; the Emory Center for Spina Bifida Research, Prevention and Policy; and UNICEF. It has been published in the June issue of the Nutrition Bulletin. The article describes, among others, the financial and emotional impact of NTDs, the cost-effectiveness of FA fortification, and the challenges to and opportunities for mandatory FA fortification in Europe.

The article reinforces IF's position that relying on prenatal screening which is followed by termination of pregnancy as the reduction of NTDs is not a real prevention strategy. Countries could and should improve periconceptional health through primary-prevention methods, such as FA supplementation and fortification.

The joint publication "Folic acid fortification of wheat flour: A cost-effective public health intervention to prevent birth defects in Europe" is available online.

Nutrition Bulletin

Positive EFSA opinion on Folic Acid Health Claim

Shine, IF member from the UK ,collaborated with industry associations and the UK Department of Health to submit an application for a health claim with regard to the beneficial effect of folate supplements

[July 2013]
The European Food Safety Authority (EFSA) has issued a favourable opinion on the use of supplemental folate to reduce the risk of neural tube defects (NTD) such as spina bifida and anencephaly.

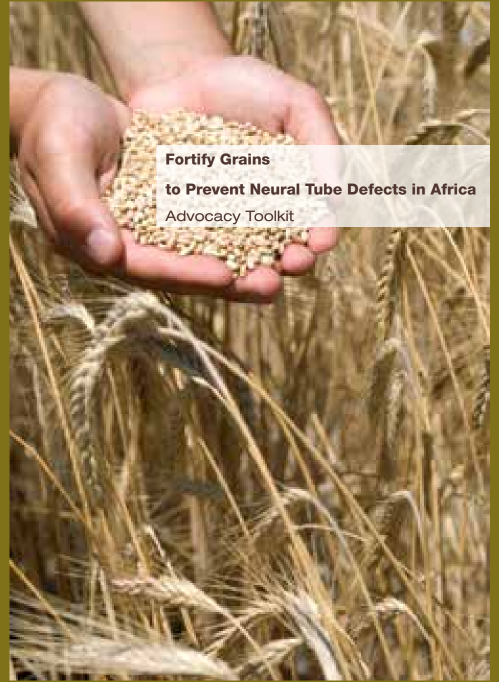
Shine CEO (and IF Treasurer) Jackie Bland warmly welcomed the news: "We are delighted to learn that EFSA has taken this very positive step and endorsed the role of 400mcg supplemental folic acid in reducing the risk of neural tube defects in pregnancy. I am confident that this will help us all in more robustly addressing what is a serious public health issue, currently affecting 1 in 1,000 pregnancies in the UK and up to 12 in 1,000 pregnancies in other parts of Europe."

Food fortification with folic acid: the new advocacy brief from the Food Fortification Initiative

38-50% of pregnancies in Europe are unplanned. Fortifying flour with folic acid reduces the birth prevalence of NTDs by an average of 46%

[August 2013]
FFI together with IF are constantly working to raise national and international awareness of the importance of Folic Acid as primary means of protection against Neural Tube Defects (NTDs). IF was represented by Dr Santosh Karmarkar at the Preparatory Meeting for Prevention, Fortification (Folic acid & Iron) and Awareness Campaign in Maharashtra for NTDs and Anaemia.

Read the new advocacy brief from the FFI.
Stay informed via the most recent FFI newsletters.



Fortify Grains
to Prevent Neural Tube Defects in Africa
Advocacy Toolkit

Fortify Grains to Prevent Neural Tube Defects in Africa: Advocacy Toolkit

The Food Fortification Initiative has recently published the Advocacy Toolkit to facilitate the flour fortification advocacy in Africa

[November 2013]
This Advocacy Toolkit provides basic information on folic acid, NTDs, and flour fortification in African context, and gives many useful contacts for organisations planning to start campaigning for a flour fortification programme in their countries.

Vitamin B9 is an essential nutrient, meaning necessary for every person in the world to maintain proper health. When inherently found in foods like spinach and lentils, this vitamin is called food folate.

When it is added to fortified foods or supplements, it is called folic acid. Amazingly, this vitamin can reduce the risk of children being affected by one of the world's most common birth defects: neural tube defects (NTDs), which develop shortly after conception, are debilitating and sometimes life-threatening. They can be treated but cannot be cured.

Continue reading the Advocacy Toolkit to find out how you can join the worldwide movement to eliminate folic-acid preventable birth defects so more children are born healthy.

Promoting the rights of people with spina bifida and hydrocephalus in Africa

Have a look at the Smarter Futures 2014 workplan highlights and learn what actions have been planned in African countries for 2014

[December 2013]
IF Secretary General Lieven Bauwens participated in a cost/benefit workshop in Tanzania to equip leaders from various African regions to calculate the economic benefit of cereal grain fortification.

The event was organized by Smarter Futures partners. It gathered participants from eastern and southern Africa, which are already fortifying flour or are in the planning stage, for example Tanzania, Zambia, Mozambique, Namibia, Botswana, Zimbabwe, Kenya, Uganda, Ethiopia, South Africa, Rwanda and Burundi. Participants represented various sectors, such as health, economic or finance ministries, National Fortification Alliances, and financial experts from milling companies.

Smarter Futures is a project that provides technical support and training for flour millers, government food control staff, and other stakeholders in Africa with regard to fortification of wheat and maize flour with vitamins and minerals. Adding vitamins and minerals to flour is economically viable and cost effective. Improving the nutritional value of people's diets through fortification of flour will improve people's health and well-being and lead to smarter futures.

HUMAN RIGHTS

European Year of Citizens 2013
www.europa.eu/citizens-2013

IF supported the European Year of Citizens Alliance

Working to promote active citizenship among the most disadvantaged

[March 2013]
The European Year of Citizens Alliance (EYCA), was formed as an open network of European and national civil society organisations willing to promote active citizenship as a core element of the European democracy in the frame of the European Year of Citizens 2013 (EYC2013). The EYC2013 was dedicated to the rights that come with EU citizenship.

Over this year, the European Commission encouraged dialogue between all levels of government, civil society and business by holding events and conferences around Europe to discuss EU rights and build a common vision of what the EU should look like in 2020. The rights of EU citizens are enshrined in the Treaty on the European Union and complement national rights. If people know about these rights and use them, they benefit as an individual. The EU feels this benefit, both economically and in terms of citizen support for the EU project. The 2010 EU Citizenship Report concluded that EU citizens are not fully benefiting from their rights because they are not aware of them – in particular the right to move and reside freely in another EU country.

The European Parliament called on the European Commission to make 2013 the European Year of Citizenship, as the MEPs wanted to boost the debate on EU citizenship and inform EU citizens of their rights. The EYCA aimed to mobilise and coordinate a wide civil society engagement throughout the year to initiate a European-wide debate on issues related to the exercise of European citizens' rights and to foster citizens' participation in the democratic life of the EU.

IF took part in the plenary and working group meetings of the European Year of Citizens Alliance (EYCA) and contributed to the working group 2 activities: the social dimension of the Europe 2020 Strategy, active inclusion, social rights and responsibilities, non discrimination and equal treatment. In 2014, some of the activities of the European Year of Citizens will continue, this time with more of a focus on the European elections (22 to 25 May).

Highly specialised care rated "very important" in the implementation of the ERN

IF and four of its member organisations participated in a public consultation on the implementation of the European Reference Networks (ERN)

[July 2013]
The consultation was held by DG Health and Consumers, to assist the European Commission in adopting conditions and criteria that the ERN, and the providers wishing to join ERN, must fulfil. The Commission needs to develop and publish criteria for establishing and evaluating ERN.

IF and its members used the opportunity to highlight the areas of importance for people with Spina Bifida and Hydrocephalus. Almost all respondents (94%) agreed that the criteria "need of highly specialised healthcare" and "based on high-quality, accessible and cost-effective healthcare" are very important for ERN.

The report only summarizes the contributions made by stakeholders to DG Health and Consumers' public consultation and gives an overview of the free-style comments that were made. It does not represent the official position of the Commission and its services.

The Directive on the application of patients' rights in cross-border healthcare (Directive 2011/24/EU) requires the European Commission to support Member States in the development of ERN between healthcare providers and centres of expertise.

The report and a list of all contributors to the public consultation can be found on the EC website.

IF joined the Fundamental Rights Platform of FRA

Through this network, participant organisations can play an active role in FRA's work

[September 2013]
IF has become a member of the Fundamental Rights Platform, the main channel for cooperation and information exchange between the European Union Agency for Fundamental Rights (FRA) and civil society. It helps to be regularly informed and consulted about the FRA's annual working programme, as well as other projects, and get the advanced access to reports and studies.

It's Our Year
give us a voice!

Active citizenship
through equal access to healthcare

What does being an active citizen mean for a person with a disability? How important is access to proper health care?

Come and listen to our stories
Tuesday 15 October
9.30 - 12.30
room A1E1

with the patronage of Mrs. Diane Dodds MEP

"It's our Year, give us a voice! " Active citizenship through the equal access to healthcare

7 networks of NGOs working on human rights gathered to discuss the access to healthcare for PwD

[October 2013]
Health inequalities among European countries and among different groups of citizens within one country create various obstacles to fulfil an active life and contribute meaningfully to society.

People with disabilities still face exclusion from the healthcare system or who have difficulties finding the appropriate treatment and care. This limited or inadequate access to healthcare can increase their marginalization in society.

Throughout our year, the European Year of Citizens we need to seize the moment and make sure that the voice of all citizens is equally heard. Especially the voice of those who are not yet fully able to be actively involved and included in society. What does active citizenship mean for a person with a disability? What are constraints and why is the access to healthcare so important?

On 15 October, under the patronage of MEP Diane Dodds and on the initiative of IF, seven organisations working for the promotion of the rights of people with disabilities gathered at the European Parliament to debate about the accessibility of healthcare.

During the meeting we heard voices from, among others, Eastern European countries sharing personal experiences of transforming the negative cycle of having a disability into a positive experience.

We heard stories on how the challenges of getting the first surgery done and collecting money for a wheelchair motivated parents to establish yearly camps to help children with spina bifida and/or hydrocephalus (SB/H) achieve the most independent life possible.

For people with SB/H of all ages the main services needed are: multidisciplinary Spina Bifida centres, specialised lifelong care, rehabilitation and training, urology, adaptive equipment, annual checks, and physiotherapy.

IF's member from the UK, Shine, pointed out major inequalities between people with the acquired spinal injuries through trauma, disease or infection and those born with SB/H. Starting from World Spina Bifida and hydrocephalus Day 2013 they planned to work to ensure that hydrocephalus is less of a 'hidden disability' and that health providers are alerted to future needs.

Healthcare providers and policy makers should raise awareness of the specific needs of people with disabilities in order to promote their better inclusion and full participation.

Limited access to good quality healthcare is not only a European problem, as was pointed out by the representatives from Africa and India. By spreading awareness on the rights of people with disabilities, we will tackle lack of access to healthcare, which leads to death, mistreatment, and no recognition of the individual's right to life.

What can the organised civil society do to close the gap between the reality and the best solutions to improve the accessibility of healthcare services for people with disabilities? Based on the meeting and IF's survey report on the Active and Healthy EU citizens common statements have been developed (see below).

Cross - border healthcare directive enters into force

European citizens will be able to take more control over their own healthcare

[October 2013]
The Cross-border healthcare directive entered into force in the whole European Union on 25 October 2013. This directive offers EU patients the right to seek healthcare, to which they are entitled in their own country, in any other EU country. This applies equally to medicinal products and medical devices where these are provided in the context of a health service.

Member States are free to decide upon the reimbursement of costs of cross-border healthcare beyond these limits. Prior authorisations for cross-border healthcare will become the exception rather than the rule. Eventually, the Directive will provide for the development of European reference networks, to encourage the pooling of knowledge and maximise the cost effective use of resources in highly specialized healthcare, such as the diagnosis and treatment of rare diseases.

IF joined EDF Expert Groups

[November 2013]
European Disability Forum committees provide assistance and advice on specific policy areas that are particularly relevant for people with disabilities. IF Secretary General Lieven Bauwens has now joined 2 EDF email Expert Groups: International Cooperation and Access to health & health stereotypes. Newborns with Spina Bifida still suffer from negative stereotyping.

Towards a democratic and more inclusive European Citizenship

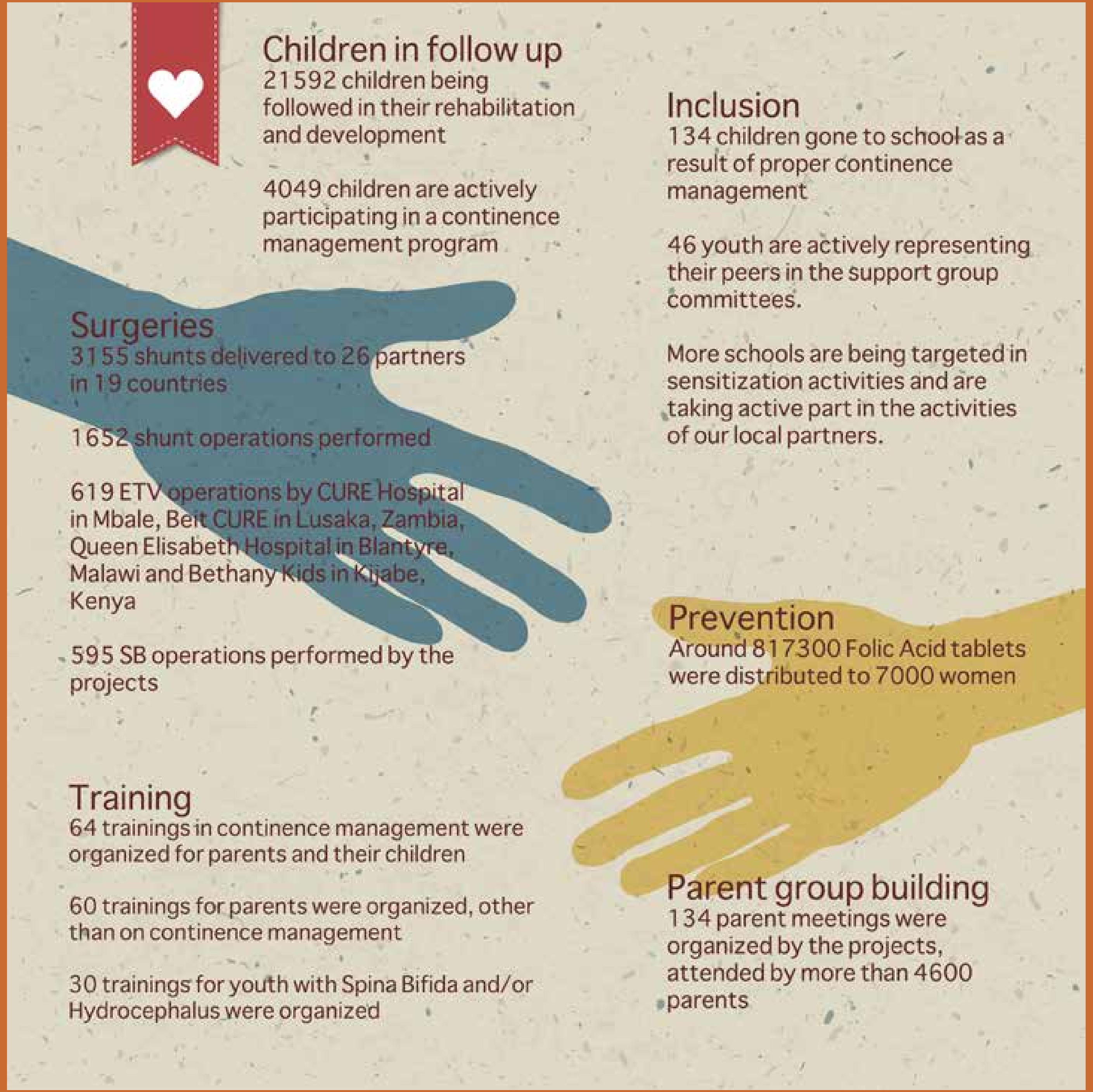
One of the recommendations: "EU institutions and Member States should adopt the proposed European Accessibility Act: improving accessibility of goods and services in the Internal Market in order to further ensure access to goods and services for all its citizens, and in particular for persons with disabilities"

[December 2013]
The closing conference of the European Year of Citizens took place in Vilnius. The event gathering over 300 people highlighted the work realized by the Alliance of 62 European networks and more than 4000 individual organisations to promote the idea of a more open, inclusive and participative Europe.

The recommendations prepared by the European Year of Citizens Alliance - to which IF contributed – were handed over by the Alliance Chair Jean-Marc Roirant to Viviane Reding, Commissioner for Justice, Fundamental Rights and Citizenship, who committed to take them into consideration in the preparation of the final report for the European Year published by the European Commission.

The recommendations were organised following a precise reasoning starting from our vision on Europe: a European Union based on solidarity, equality and participation. This vision implies that vulnerable, marginalised and excluded citizens are equally involved and included in society, notably in terms of participation. It is also based on strengthening the three democratic pillars that are:
- education and information;
- open and responsive institutions;
- strong and independent civil society.

INTERNATIONAL SOLIDARITY



Children in follow up

21592 children being followed in their rehabilitation and development

4049 children are actively participating in a continence management program

Surgeries

3155 shunts delivered to 26 partners in 19 countries

1652 shunt operations performed

619 ETV operations by CURE Hospital in Mbale, Beit CURE in Lusaka, Zambia, Queen Elisabeth Hospital in Blantyre, Malawi and Bethany Kids in Kijabe, Kenya

595 SB operations performed by the projects

Training

64 trainings in continence management were organized for parents and their children

60 trainings for parents were organized, other than on continence management

30 trainings for youth with Spina Bifida and/or Hydrocephalus were organized

Inclusion

134 children gone to school as a result of proper continence management

46 youth are actively representing their peers in the support group committees.

More schools are being targeted in sensitization activities and are taking active part in the activities of our local partners.

Prevention

Around 817300 Folic Acid tablets were distributed to 7000 women

Parent group building

134 parent meetings were organized by the projects, attended by more than 4600 parents

Saudi Arabia offers generous support to children with Spina Bifida and Hydrocephalus in Tanzania

The chairman of ASBAHT, Mr Abdulhakim Bayakub, received praise for his endless efforts to make sure that children with SB/H get proper care and that society fully includes them

[May 2013]
The Royal Kingdom of Saudi Arabia has donated modern medical equipment, invaluable for the surgical treatment of children with SB/H. The aid has come after a call from the Association for Spina Bifida and Hydrocephalus Tanzania (ASBAHT) in collaboration with the Muhimbili Orthopaedic Institute (MOI).

Through parent meetings, organised by ASBAHT and supported by MOI, the stigma associated with SB/H is slowly being overcome. MOI received an ultrasound machine, anaesthetic machine and a ventilator. The Saudi government will continue to assist Tanzania in the health sector due to the good relationship the two countries have.

IF at 6th session of the Conference of States Parties to the CRPD

IF took part in the pre-conference Civil Society CRPD Forum that took place in New York to mainstream disability in the development agenda

[July 2013]
This year's forum was coordinated by the International Disability Alliance with the support of Disabled People's International, Disability Rights Fund, the Global Partnership for Disability and Development, Human Rights Watch, the International Development and Disability Consortium, and Rehabilitation International.

Panellists and participants (civil society organization representatives, mostly from DPOs) engaged in a debate with other stakeholders on a number of thematic issues that focused on the overarching theme that the post-2015 development agenda must be inclusive of the rights and participation of persons with disabilities.

The session focused on the practical steps for the inclusion and participation of the disability community in the Post 2015 Agenda, exploring the experiences of DPOs in the Global South and shared lessons form various national and regional projects. The forum concluded that the discussion and consultation process should incorporate persons with disabilities and DPOs at all levels of society and at all stages, from grassroots discussion and Government consultations, to the United Nations international forum.

A number of other side events took place on 16-19 July. These events looked at different ways to create an inclusive environment where persons with disabilities can fully participate. UNICEF organized a debate on Measuring Disability, Inclusion International on The Right to Decide = true empowerment of people with intellectual disabilities, and IDA together with the Government of Israel on Persons with Disabilities' role in Developing Accessible Environments.

Increased focus on people with disabilities in development strategies

The estimated one billion people worldwide who live with disabilities are still excluded from equitable access to resources (education, healthcare) and as a result persons with disabilities experience disproportionately high rates of poverty

[September 2013]
Under the theme: "The way forward: a disability inclusive development agenda towards 2015 and beyond", the high-level meeting of the General Assembly on disability (HLMD) comprised of a plenary meeting and two consecutive informal interactive round tables.

Participation in each round table included Member States, observers and representatives of entities of the United Nations system, as well as representatives of civil society, organizations of persons with disabilities and the private sector. IF was represented at this event by its Secretary General Lieven Bauwens.
The HLMD resulted in a concise, action-oriented outcome document in support of the aims of the Convention on the Rights of Persons with Disabilities and the realization of the Millennium Development Goals and other internationally agreed development goals for persons with disabilities.

While the Millennium Development Goals (MDGs) represent a concerted effort to address global poverty, there is a striking gap in the current MDGs and their inclusion of persons with disabilities. In spite of the adoption of the Convention on the Rights of Persons with Disabilities in 2006, disability remains largely invisible in most mainstream development processes.

Annual African workshop

More than 70 participants gathered for yet another IF African Workshop. The workshop theme was S.H.I.P: progress and planning

[October 2013]
Participants came from all IF partners in Africa - Uganda, Kenya, Tanzania, Sudan, Zambia, and Malawi - and from Belgium, Norway, Sweden, Germany and Canada. Amongst them were parents, youth and young adults, SHIP coordinators and other experts working with people with spina bifida and hydrocephalus.

The objectives of the workshop were:
- to evaluate progress made after implementation of SHIP;
- to start planning for the next steps to ensure further implementation;
- to include youth and young adults in SHIP.

S.H.I.P.

2013 was the year of first implementation, of informing stakeholders about the model, and the use of the S.H.I.P. Passport. By the end of 2013, the SHIP Passport was in use in Kenya, Uganda, Tanzania, Malawi and Zambia.

S.H.I.P. will remain the key objective of IF's work in international solidarity, a coordinated, multidisciplinary approach towards an individualized care program. By linking medical and lifelong care, continuity and quality of care can be ensured.

New Swedish team in International Solidarity

IF's member RBU has been involved in our work in Tanzania for many years. In 2013, the team changed and we are happy to welcome a new group of enthusiastic parents and youth from RBU:

- Liiso and Ina Akerberg
- Ammi Sundqvist-Andersson
- Stefan Andersson
- Ewa Wodzynski
- Gerda Lindholm

Spina Bifida and Hydrocephalus Association Kenya

We are proud that SHAK, our Kenyan partner, has finalized its registration as a national organization in October 2013. The national office serves as an umbrella to 11 branches nationwide.

IF at ISPN meeting

[September 2013]
IF participated in the annual ISPN conference in Mainz, Germany (International Society for Paediatric Neurosurgery).

Mrs. Kordelia Fischer-Borchert, IF's expert in CBR and member of our working group IS, presented IF's work in developing countries and its effort to implement S.H.I.P.

NETWORK DEVELOPMENT

IF has become a full member of EURORDIS alliance

EURORDIS aims at improving the quality of life of people living with rare diseases in Europe through advocacy at the European level, support for research and drug development, networking patient groups, raising awareness and other actions designed to fight against the impact of rare diseases on the lives of patients and family

[February 2013]
IF's full membership application has been approved by the EURORDIS Board of Directors. Through its membership, IF joined an alliance of more than 500 patient organisations, all dedicated to improving the quality of life of people living with rare diseases in Europe.

EURORDIS represents 30 million patients affected by 4000 distinct rare diseases and advocates for policies that address the needs of patients and their families within the European Commission and other European institutions.

In 2011, IF and EURORDIS already joined forces during the launch event of IF's publication "Act against Europe's most common birth defects: The right advice at the right time can reduce Neural Tube Defects now".

1st Baltic conference on multidisciplinary care

[May 2013]
IF's member organisation from Estonia organised the 1st Baltic conference on multidisciplinary care for people with Spina Bifida and/or Hydrocephalus, in cooperation with IF. Target groups of the conference were healthcare professionals involved in the field of Spina Bifida and Hydrocephalus.

The conference focused on the latest scientific developments in medical treatment, as well as on the psychological and social issues involved. Experts from multidisciplinary clinics presented the experiences in various countries, including the United Kingdom, Germany and Estonia.

A Song, A City - raising awareness of Spina Bifida and Hydrocephalus

[June 2013]
Canadian born musicians Danny Lamb and Jay Baty spent the month of June writing songs and traveling through Europe to raise awareness of Spina Bifida and Hydrocephalus. Danny was diagnosed with both conditions at age 3, and plays an invaluable role as the Youth Ambassador for the Spina Bifida and Hydrocephalus Association of Ontario (SB&H). He travelled with IF to Uganda, Stockholm, Tanzania and Izmir to inspire and connect with youth with SB/H through his music.

Danny and Jay reached out to people with SB/H and their families in Ireland, England, Scotland, the Netherlands, Belgium and Turkey. They wrote a song in each city they visited and shared it through social media. At the end of their tour, Danny and Jay attended IF's 24th International Conference in Izmir, where they conducted a music workshop, resulting in the "PUSH song".

1st LATAM Network for SBH established by APEBI

[August 2013]
IF representative member from Argentina, APEBI, initiated the creation of the Latin American and Caribbean Network for Spina Bifida and Hydrocephalus. Argentina Foreign Ministry was the meeting place where representatives from several Latin American countries and several provinces pledged to work together to improve the quality of life of people with spina bifida and hydrocephalus in the region.

Towards a Spina Bifida & Hydrocephalus network in China

The incidence of Spina Bifida and Hydrocephalus in China is high, as is childhood mortality due to these conditions.

[June 2013]
In Beijing, all stakeholders in the field of care attended the first network meeting on the treatment and care of Spina Bifida and Hydrocephalus in China. The event was a joint initiative of China Disabled Persons' Federation (CDPF), China Rehabilitation Research Center (CRRC) and IF.

Driving Force is large group of survivors determined to fight for access to decent care for all persons with SB&H in China. Their leader Mr Sun Hongwei emphasized the urgent need for better care and treatment. Mrs Sun Shujun, who has Spina Bifida herself and who was a member of the Chinese parliament, said that the need for a national Chinese Spina Bifida association is evident. She expressed the wish to join the IF Network.

The China Disabled Persons' Federation (CDPF) and IF held a seminar on the care for children and adults with Spina Bifida and Hydrocephalus at the China Rehabilitation Research Center (CRRC) in Beijing. Many experts gave high-level speeches. The need to translate the available knowledge and care in services that reach the whole target group requires coordinated action. CRRC decided to create a centre for treatment within their hospital that can one day become the training centre for the whole country. Professor Li Jianjun said that this seminar was the first real step for a Chinese network of care and prevention for Spina Bifida and Hydrocephalus.

The China Disabled Persons' Federation (CDPF) and IF met to evaluate further action for persons with Spina Bifida and Hydrocephalus (SB/H) in China. CDPF Vice Chairperson Mr Lu Shiming expressed his appreciation for IF's efforts to organise a successful high-level network for SB/H in Beijing. With the China Rehabilitation Research Center (CRRC), China has all the potential to serve our target group at international quality standards. However, action is needed to ensure access to care for all. A disability specific group within the CDPF structure would be helpful towards this goal. Mrs You Hong's presence was of great importance, as Director-General of the Rehabilitation Department of CDPF she can have an impact in all levels of society. Mrs Sun Shujun and Mr Sun Hongwei, both representing our target group, experienced this meeting as a milestone towards a better future for children with SB/H in China.

[September 2013]
In follow-up to the first network meeting on treatment and care of Spina Bifida and Hydrocephalus, IF President Margo Whiteford and former IF President Pierre Mertens were invited to lecture at the 8th Beijing International Forum on Rehabilitation. At this very well attended meeting, Margo Whiteford explained the development of neural tube defects and the impact on daily life of having Spina Bifida.

For the first time a special half-day session was held on SB/H during the forum. The cooperation with China Disabled Persons' Federation (CDPF) will continue to raise awareness about SB/H, to remove negative stereotypes, and to improve access to healthcare. Efforts are also aimed at establishing a SB/H disability specific working group within CDPF's association of the physicaly disabled.

IF's 24th International Conference "Unite & Share"

IF's 24th International Conference took place on June 28 and 29 in Izmir, Turkey. The conference was hosted by IF's member organisation from Turkey, Spina Bifida Dernegi

[June 2013]
IF's 24th International conference was a great success and was well attended by representatives of IF member organisations and local people engaged in the field of Spina Bifida and Hydrocephalus. Participants from all over the world gathered in Turkey for two days to share the latest information.

The conference was organised around lectures, creative and thematic workshops and networking activities. Numerous members attended IF's Workshop on Fundraising for Non-Profit Associations. Special honour was given to parting IF President Pierre Mertens, for his dedication and his relentless efforts to improve the lives of those born with Spina Bifida and Hydrocephalus. Some of the lectures were published online together with the presentations. You can see all recorded material on IF's YouTube channel.

IF elects new board members and president

Margo Whiteford from the Scottish Spina Bifida Association has been elected as next IF President

During our General Assembly held in Izmir, Margo Whiteford was elected as IF president for the 2013-2015 period. She succeeded Pierre Mertens at the expiry of his statutory term of office that he performed since 1995. Pierre will continue his work in the field of Spina Bifida and Hydrocephalus as director of Child-Help, a Belgian NGO.

Holding the position as Chairperson of the Scottish Spina Bifida Association for 8 years, and having become its medical advisor, Margo Whiteford has regularly proven a great expertise and is in contact with various disability support groups and voluntary organisations. She was born with Spina Bifida, and now works in Glasgow as a consultant clinical geneticist, with an interest in the aetiology of neural tube defects. Through her clinical practice Margo meets many people with Spina Bifida and/or Hydrocephalus of all ages.

"I'm happy to be taking on the leadership of IF when it has been built up to such a healthy state by the two Presidents who have gone before me. As a person with Spina Bifida who is also a doctor and Chairperson of a Spina Bifida association, I hope to be able to draw on my own experiences, to help improve the quality of life for other people with Spina Bifida and Hydrocephalus all over the world. I realise that leading an international organisation will be a challenge but I am lucky in having Board members from four different continents, and from a variety of backgrounds to support me in this task. With the development of PUSH it will be exciting to watch the IF community and network expand and I look forward to being part of it." said Margo Whiteford after the elections.

"It is with great faith that I hand over this function to Margo. The background of the first two chairpersons was having daughters with Spina Bifida. The next president IS a daughter with Spina Bifida. I could not have wished for more" announced outgoing IF President Pierre Mertens.

Inspired by his daughter Liesje, he became committed to IF and initiated various successful programmes for international solidarity, inclusive education, and art and disability projects. Under his leadership IF grew from a small federation to an internationally recognised NGO with professional staff and stable funding.

The General Assembly elected new members of IF's Board:

- Dr Santosh Karmarkar (India), representing the Indian Spina Bifida Association.
- Lumbwe Chiwele (Zambia), representing the Zambian Spina Bifida and Hydrocephalus Association.
- Emine Nurdan Anli (Turkey), representing the Turkish Spina Bifida and Hydrocephalus Association
- Maarit Fjellhaug Nylund (Norway), representing the Norwegian Spina Bifida and Hydrocephalus Association.

Global expansion of the IF Network

We are very happy to broaden and strengthen our network throughout Europe, Africa and Asia and look forward to the cooperation with all IF member organisations. Together we can improve the lives of those born with Spina Bifida and Hydrocephalus!

In 2013, four organisations expressed the wish to join the IF network and applied for IF membership. During IF's General Assembly the expansion of the IF Network was approved by welcoming the following new members:

- Spina Bifida Foundation India,
- Spina Bifida ir Hidrocefalija asociacija Lithuania,
- the Festus Fajemilo Foundation in Nigeria,
- the Spina Bifida and Hydrocephalus Association Kenya (SHAK).

Pierre Mertens received IF Award 2013

It was the unanimous decision of the IF Board that the person most deserving of the IF Award 2013 is its outgoing President Pierre Mertens. When his daughter Lies was born with Spina Bifida in 1978, and Pierre and his wife Mol discovered that there was a lack of information for parents of children with Spina Bifida and Hydrocephalus, they founded the Belgian association for Spina Bifida. In 1993, as the Vice-President of IF, he set up the International Solidarity group. Through this, Pierre has improved the medical care and training programmes for children with Spina Bifida throughout third world countries, both in Africa and Asia, more recently by setting up a network in China.

It is through Pierre's leadership that IF obtained high recognition as an NGO that it has today. He is without a doubt someone who has made an outstanding contribution in the field of Spina Bifida and Hydrocephalus. We thank Pierre for the many years he served as IF's President and for his strong commitment and great achievements.

World Spina Bifida and Hydrocephalus Day: launch of PUSH!

The World Spina Bifida and Hydrocephalus Day has been established and designated by IF's General Assembly in Guatemala 2011 with the aim of raising awareness and understanding about Spina Bifida and Hydrocephalus. It serves also as means to advocate and promote the rights of persons with these impairments

[25 October 2013]
For the second time in history, all around the world many IF members, foundations and NGOs organised events to mark the World Spina Bifida Day. Activities varied from conferences, workshops, marathons, awareness weeks to concerts and gatherings for the families.

In Bulgaria for example LUMOS and IF coorganised a workshop on the "Treatment and Experiences of Children with Hydrocephalus in Bulgaria and their Families". The second day was fully focused on building the capacity of parents' organisations to campaign and raise awareness of hydrocephalus treatment and related issues. The World Spina Bifida day in Uganda was celebrated at regional level by IFs partners in Kampala, Gulu, Mbarara, and Mbale. The parents support groups working together with the SHIP coordinators organised activities in their areas. In Kampala in the central region, radio spots were run on the local radio stations and a talk show was held to sensitize the public on SBH and share experiences of parents and youth.

In Brussels the 2013 edition started already on 15 October where IF together with partner organisations organised a conference at the European Parliament on the access to healthcare.

PUSH!

On 25 October 2013, the brand new initiative - PUSH! was launched. PUSH stands for People United for Spina bifida and Hydrocephalus and is the online community and campaigning platform for all people concerned with SB/H across the world: individuals with SB/H, parents, families, professionals, specialists, care organizations and others interested in the field.

www.pu-sh.org

PUSH! is a global community where there is a place for every individual with spina bifida and hydrocephalus, every family, evey professional fighting for better services, every individual who cares about these issues.

What is PUSH?

We are aware of enormous challenges and issues that people with spina bifida and hydrocephalus face. These issues come from small organisations lacking proper communication strategies and staff who could dedicate time to make their voice be heard and push the stories forward.

The inequalities in healthcare almost all over the world and the terrible neglect of the fact that many people with spina bifida and hydrocephalus are growing older with no regulation or agreement about how their needs can be met. Even in the most developed countries where healthcare is excellent, there are other emerging issues.

When people have something so fundamental in common, across all nationalities and creeds, then great strength can be gained from forming a united bond with global reach. That's why we formed PUSH! – People United for Spina Bifida and Hydrocephalus.

Why join PUSH?

Through the PUSH online platform we can support one another by:

- sharing information and knowledge;
- giving our skills and expertise to one another
- building the world's biggest resource of life experience with SB/H;
- forming networks of like - minded people to bring about change;
- coming together to meet and support each other.

PUSH is not a tool for fundraising. Its objective is to focus on non-financial rewards for campaigns and to create a vast community for information sharing. We use campaigning, advocacy, political skills and the authority of a truly international community to bring about change by:

- organising campaigns that represents thousands and thousands of voices across the world;
- giving international support in order to strengthen and highlight national or regional campaigns in member states;
- offering our support and encouragement to local groups, wherever they may be in the world, who are working towards improvement or to challenge injustice and inequality.

Become a member:

- to immediately join the first global community of people affected by SBH;
- to be able to access members of the PUSH community as it grows to find out where there are people who share the same concerns/ life experiences;
- to be invited to push for campaigns and policies designed to improve life of people with SBH around the world;
- the membership is free and only you are in charge of your campaign!
- you can translate the website and help us grow (so far we have English, French and Spanish language versions);
- join as a National Coordinator and get involved in the communication and campaigning trainings;
- use our vast social media audience to PUSH your message!

PUSH! in 2 steps:

- Join the movement!
- Take action and start your own campaign!

FINANCIAL RESULT IN 2013

Statement of the auditor

Report of the auditor on the financial statements for the year ended 31.12.2013 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 31-12-2013, prepared under the responsibility of the board of directors of the federation, which show a balance sheet total of € 585.014,19 and a loss for the year of € 16.526,31.

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 31/12/2013 give a true and fair view of the federations assets, liabilities, financial position and results of operations.

Additional certifications and information

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

Without prejudice to formal aspects of minor importance, the accounting records were maintained in accordance with the legal and regulatory requirements applicable in Belgium. Otherwise, we do not have to report to you any transactions undertaken or decisions made in violation of the bylaws or the articles of the Law on Non-Profit Organisations.

Lennik, March 20th 2014
Roger De Nul
Auditor

Balance sheet on 31 December 2013

Assets	31-Dec-2013	31-Dec-2012
TANGIBLE ASSETS	3,058.87 €	3,548.00 €
IT & office supplies	1,812.53 €	1,586.09 €
Office furniture	715.55 €	1,431.12 €
Cautions	530.79 €	530.79 €
AMOUNTS RECEIVABLE	183,046.99 €	91,950.41 €
Debtors	69,874.60 €	57,008.50 €
Invoices to make	21,412.06 €	0.00 €
Advances	1,121.97 €	266.38 €
Dubious debtors	29,548.66 €	6,910.07 €
Depreciations dubious debtors	-14,456.27 €	-6,910.07 €
Subsidies to receive	29,961.06 €	30,000.08 €
Child-Help current account	45,584.91 €	4,675.45 €
BANK & CASH ACCOUNTS	396,786.00 €	709,137.09 €
KBC - long term accounts	0.00 €	20,000.00 €
KBC - accounts	4,757.57 €	10,760.39 €
KBC - accounts saving	391,118.22 €	678,255.76 €
PayPall	0.00 €	120.94 €
Internal transfers	910.21 €	0.00 €
TRANSIT ACCOUNTS	2,122.33 €	131.58 €
Costs for next year	2,122.33 €	131.58 €
Total assets	585,014.19 €	804,767.08 €

Liabilities	31-Dec-2013	31-Dec-2012
RESERVES	237,318.98 €	253,845.29 €
Funds of IF	253,845.29 €	248,347.70 €
Profit-loss bookyear	-16,526.31 €	5,497.59 €
AMOUNTS PAYABLE	119,332.18 €	80,082.08 €
Suppliers	57,315.47 €	5,785.00 €
Taxes to be paid	1,494.00 €	3,287.27 €
Social charges to be paid	0.00 €	1,734.69 €
Salaries to be paid	1,966.37 €	5,121.17 €
Provision holiday fee	23,142.49 €	20,245.08 €
Projects current accounts	31,099.01 €	43,908.87 €
Diverse to pay	4,314.84 €	0.00 €
TRANSIT ACCOUNTS	243,363.03 €	470,839.71 €
Profits for next year	243,363.03 €	470,839.71 €
Total Liabilities	600,014.19 €	804,767.08 €

Profit and loss 2013

OUT

Costs

Housing costs	22,618.84 €
Office supplies	3,765.86 €
Publications	3,506.98 €
Communication costs	4,164.31 €
Website	8,827.90 €
Transport costs	275.72 €
Insurance	1,153.40 €

Fees

Membership fees	2,375.00 €
Volunteers	1,079.41 €
Translation	504.50 €
Bookkeeping	3,775.69 €
Audit	1,542.75 €
Lawyer	476.25 €
Social secretariat	5,318.95 €
Medical secretariat	1,199.79 €
External evaluation	1,998.00 €
Consultants - Food Fortification	36,800.37 €
IT support	1,364.88 €
Other fees	1,027.16 €

Travel

Travel	131,845.47 €
Subsistence	35,706.00 €
Conferences / meetings	115,994.18 €

Projects

Medical material	28,867.19 €
Salaries	80,442.42 €
Training	36,778.75 €
Prevention, Treatment & Rehabilitation, Parent Meetings and other costs	79,846.02 €

Salaries

Salaries (secretariat)	342,292.81 €
Consultant - China	14,200.00 €
Consultant - Uganda	11,104.87 €

Depreciations	9,564.33 €
Financial costs	1,503.08 €
Exceptional costs	495.63 €

IN

Membership fees	9,600.00 €
Subsidy Norad (through RHF)	258,545.00 €
Subsidy MyRight (through RBU)	65,023.82 €
Subsidy European Commission (Progress)	149,805.31 €
Subsidy Dutch Ministry of Foreign Affairs (Smarter Futures)	255,056.17 €
Contribution Bayer Healthcare	50,000.00 €
Contribution Bühler	60,956.73 €
Contribution Child-Help	57,657.82 €
Other grants	8,148.34 €
In-kind benefits	180.00 €
Recuperation of costs	55,988.41 €
Financial income	2,928.60 €

TOTAL COSTS: 990,416.51 €

TOTAL INCOME: 973,890.20 €

RESULT: -16,526.31€

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The contents of this publication are the sole responsibility of the International Federation for Spina Bifida and Hydrocephalus and can in no way be taken to reflect the views of the European Commission.

IfSBH
INTERNATIONAL
FEDERATION
for
SPINA BIFIDA
and
HYDROCEPHALUS

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