



INTERNATIONAL FEDERATION
FOR SPINA BIFIDA
AND HYDROCEPHALUS

ANNUAL REPORT 2014





MESSAGE FROM THE PRESIDENT

Dear Friends

It has been another exciting year for me, as President of IF. Last year I told you about the meeting we had with other international organisations with an interest in people who have spina bifida, and/or hydrocephalus (SBH) and this year I am pleased to report that this united group has agreed to form the **PUSH Alliance** and make our community even stronger. We have also been able to form a **Global Experts Panel** of six people with expertise in different fields related to SBH and we had a very positive face-to-face meeting in Boston earlier this year.

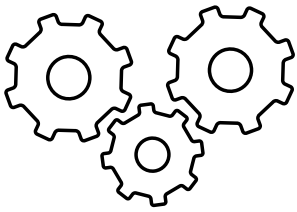
I am pleased to report that IF has been successful in obtaining funding for a further three years for our **work in Europe** which will allow us to continue to organise workshops on a variety of topics in various parts of Europe. We are also continuing to make progress in other parts of the world thanks to the funding which we receive from a number of countries and the hard work of our staff based in Europe, China, South America and Africa.

Our **International Conference** in Buenos Aires last June was a great success, very well attended by families from all over South America. The plans for our next International Conference in Milan, which we have moved to October, to coincide with the World Spina Bifida Day, are now starting to take shape.

We have many more plans for IF in the coming years and I look forward to updating you about these next year but for now I would like to take this opportunity to thank my fellow Board members for their continued support and all the staff of IF for doing such a wonderful job.

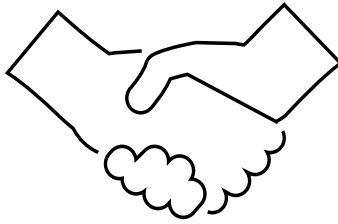
MARGO WHITEFORD, IF PRESIDENT

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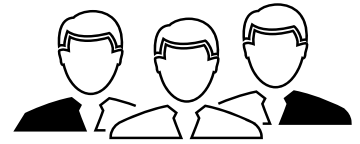
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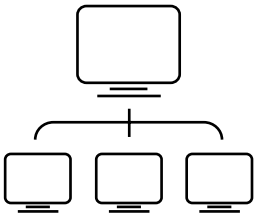
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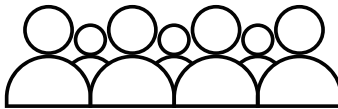
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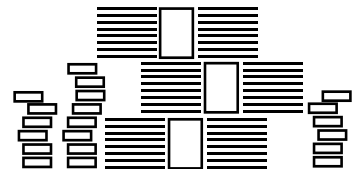
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ABOUT IF

The International Federation for Spina Bifida and Hydrocephalus (IF) was founded by people with spina bifida and hydrocephalus (SBH) and their families in 1979. Over the years, it has grown from a voluntary association into a professional disabled people's organisation (DPO) with global coverage, democratic structure and transparent and accountable processes.

The majority of IF member organisations are led and governed by adults with SBH or parents of children with SBH. Children are active participants in our members' activities: they are involved in child-led activities, training workshops on independence and holiday camps. Nowadays, many young people with SBH have taken over the leadership of their organisations. In most cases, IF members choose close cooperation with medical and education professionals and researchers, given the importance of these professions to children and adults with SBH for their survival and development.

IF's fast-growing membership now includes 51 member organisations in Africa, Australia, the Americas, Asia and Europe. Membership of IF is open to all nationally registered organisations that share IF's vision and mission and actively involve people with SBH in their work.

In its work, IF is supported by the **Global Experts Panel** (GEP) and its Network. The Network is a multidisciplinary scientific advisory body to IF's Board of directors, the GEP a 7-person steering group of the wider Network. The individual GEP members are IF spokespersons on various topics, and are respected global experts in their field of expertise in top-level institutions.

PUSH Alliance has grown out of the informal PUSH community of individuals and professionals, and now includes a wide range of global institutional stakeholders working together to exchange information and advocacy materials, collect and publish data and promote the latest research on SBH.



VISION

Our vision of the future is a society that practices primary prevention of neural tube defects and hydrocephalus, guarantees human rights of children and adults with SBH, and celebrates their contribution in all areas of life.



MISSION

The mission of IF is to reduce the incidence of spina bifida and hydrocephalus by primary prevention, and to improve the quality of life of people with SBH and their families through human rights education, political advocacy, research and community building.



VALUES

Human rights: promotion and protection of human rights of people with SBH in accordance with the UNCRPD is our highest value.

Transparency and accountability: we work in a transparent and inclusive way, fully accountable to our members, donors and external stakeholders.

Participation: we take the views of children and adults with SBH, and their families into account and rely on them in our work.

Cooperation: we are open to building constructive and durable relations with international, regional and national bodies, NGOs, professional associations and other stakeholders who share our vision and goals.

Inclusiveness: we respect the regional, cultural and socioeconomic specificities of our global members, and promote a tailored approach to working on SBH issues.



Around the world, IF mobilizes the power of People United for Spina Bifida and Hydrocephalus



Visit: www.ifglobal.org/members

STRENGTHENING THE MEMBERSHIP

List of the official IF members:

- **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 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
- **Hungary** MEOSZ
- **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
- **Kenya** Spina Bifida and Hydrocephalus Association Kenya (SHAK)
- **Lithuania** Spina Bifida ir Hidrocefalija asociacija
- **Luxembourg** Association pour le Spina Bifida a.s.b.l.

- **Mexico** Asociación Mexicana de Espina Bífida A.C. (AMEB)
- **Mongolia** Mongolian Spina Bífida Foundation “Maral Angel”
- **The Netherlands** BOSK Work Group Spina Bífida & Hydrocephalus
- **Nigeria** Festus Fajemilo Foundation
- **Norway** Ryggmargsbrokk- og hydrocephalusforeningen
- **Peru** Asociación de Espina Bífida e Hidrocefalia del Perú (ASESBIH)
- **Poland** Fundacja “Spina”
- **Portugal** Associação e Spina Bífida e Hidrocefalia de Portugal (ASBIHP)
- **Romania** Asociația Română de Spina Bífida e Hidrocefalie (ARSBH)
- **Russia** Association of Spina Bífida and Hydrocephalus of St. Petersburg
- **Scotland** Scottish Spina Bífida Association (SSBA)
- **Serbia** Spina Bífida and Hydrocephalus association of Serbia
- **Slovakia** Slovenská spoločnosť pre Spina Bífida a/ alebo Hydrocefalus, o. z.
- **Spain** Federación Española de Asociaciones de Espina Bífida e Hidrocefalia (FEBHI);
Asociació Catalana d’Espina Bífida i Hidrocefalia (ACAEBH);
Asociación Madrileña de Espina Bífida e Hidrocefalia (AMEB)
- **Sudan** Spina Bífida Federal Association
- **Sweden** RBU, Spin-Off
- **Switzerland** Schweizerische Vereinigung zugunsten von Personen mit Spina Bífida und Hydrocephalus (SBH)
- **Turkey** Türkiye Spina Bífida Derneni
- **Uganda** Central Uganda Spina Bífida and Hydrocephalus Network
- **UK** SHINE
- **USA** Spina Bífida Association of America (SBAA); Hydrocephalus Association;
Pediatric Hydrocephalus Foundation

OUR BOARD



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ANLI, TURKEY



ELENA ZAPPOLI
ARGENTINA

OUR SECRETARIAT

- LIEVEN BAUWENS Secretary General
- JANINA ARSENJEVA European Programme Manager
- BECKY HANDFORTH Europe Associate, FFI
- RENÉE JOPP Information Officer
- EWA KAMPELMANN Communications Officer
- ANNA MAARIT PAAKKULAINEN PA /Administrator
- KATALIJNE VAN DIEST Programme Manager, International Solidarity
- ANNA VERSTER - Senior Advisor, Fortification

IF volunteers in 2014: ERIC HOLDTGREFE, VERA COSTA, ANISSA KATTI, MARTA ALBERTINI



EXTERNAL COOPERATION

At IF we build on the experience of our member organisations as we listen to the needs of organisations at grassroots level to channel these to policy and decision makers at EU level. Many of the issues we are working on are also priorities for other international organisations, and we believe in positive cooperation to have an even greater impact on international policies and programmes.

The International Federation for Spina Bifida and Hydrocephalus holds Special Consultative Status at the **Economic and Social Council of the United Nations** and Participatory Status at the **Council of Europe**. Since 2011 Lieven Bauwens, IF Secretary General represents IF in the Executive Management Team of the **Food Fortification Initiative**.

Besides our member organisations, we regularly link up to other networks to exchange best practice, and also grow our network, on which we rely for our events, projects and advocacy work.

The International Federation for Spina Bifida and Hydrocephalus has vastly enlarged its international network.

In 2014 IF was cooperating with the following

international bodies:

- 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)
- European surveillance of congenital anomalies (EUROCAT)
- Food Fortification Initiative (FFI)
- The Global Alliance for Improved Nutrition (GAIN)
- European Disability Forum (EDF)
- The European Organisation for Rare Diseases (EURORDIS)
- International Disability and Development Consortium (IDDC)
- European Union Agency for Fundamental Rights (FRA)
- Liliane Fonds
- Bethany Kids
- CURE International
- Association of Volunteers in International Service (AVSI)
- WHO Partnership for Maternal, Newborn & Child Health (PMNCH)
- Handicap International (HI)
- Helen Keller International (HKI)
- Atlas Alliance
- MyRight

Companies

- Akzo Nobel
- B BRAUN Medical
- Bühler
- Surgiwear

GLOBAL EXPERTS NETWORK

We are actively engaged in a number of working and expert groups to which we bring the knowledge and needs of the families of people with SBH across the world. We want to stay informed about current developments and trends of importance in the field of Spina Bifida and Hydrocephalus, and encourage further research to improve the quality of life of persons born with these conditions and reduce the incidence of Spina Bifida and Hydrocephalus by primary prevention. To this end we are currently developing a Global Experts Network on Spina Bifida and Hydrocephalus, which is steered by a newly established Global Experts Panel.

Composition of the **Global Experts Network**:

- **Ronald Afidra**, FFI Africa Network Coordinator
- **Femke Bannink**, Senior Advisor/ Researcher
- **Richard Bransford**, general surgeon, MD, FACS
- **Myleen Christiaens**, consultant on Spina Bifida
- **Filippo Ciantia**, tropical medicine, Expo 2015
- **Kordelia Fischer-Borchert**, consultant, community-based rehabilitation
- **Philippe Gillis**, consultant paediatrics and tropical medicine
- **Helen Healy**, consultant life skills and transition
- **Marisol Hernandez**, IF liaison in Buenos Aires
- **Bo Hjelt**, consultant fundraising and general management
- **Liu Jiarong**, IF liaison in Beijing
- **Joe Mulinare**, prevention expert, former CDC
- **Koen Sevenants**, senior advisor, Development Cooperation Asia
- **Carla Verpoorten**, medical consultant, neuro-paediatrician
- **Patrick De Vlieger**, anthropology and disability

Composition of the **Global Experts Panel**:

- **Margo Whiteford**, Chair
- **Benjamin Warf**, Services and Care
- **David Nolan Morrissey**, Human Rights
- **Amy McPherson**, Social Inclusion
- **Richard H. Finnell**, Genetics
- **Anne Molloy**, Causes
- **Klaus Kraemer**, Public Health



OUTREACH



Our monthly newsletter grew from 3,063 to **5,211 READERS**



The number of likes on our page **FACEBOOK.COM/IFSBH** grew from 1,840 to **2,899** with a weekly reach of over 4,000 visitors



@IFSBH TWITTER ACCOUNT now has **1127 FOLLOWERS** (was 353 last year)



IFGLOBALORG YOUTUBE CHANNEL received more than **4,100 VIEWS** in 2014



WWW.IFGLOBAL.ORG was visited **48718 TIMES** in 2014 by visitors from 173 different countries



Around **400** participants (+200 online) attended IF's 25th International Spina Bifida & Hydrocephalus Congress "GENERating Changes" in Buenos Aires



Our **ONLINE PUBLICATIONS ISSUU.COM/IF-SBH** were read **2905** times

INTERNATIONAL SOLIDARITY

TRAINING

63 trainings in continence management were organised by our local partners for parents and their children
87 trainings for parents, other than on continence management
47 trainings and meetings for youth with Spina Bifida and/or Hydrocephalus

SURGERIES

2515 shunts delivered to **37** partners in **26** countries
1603 shunt operations performed by the projects
700 ETV operations performed in Mbale, Beit; Lusaka, Zambia; Blantyre, Malawi and in Kijabe, Kenya
665 SB operations performed by the project partners

CHILDREN IN FOLLOW UP

23 785 children being followed in their rehabilitation and development
4 665 children are actively participating in a continence management program

SUPPORT GROUP BUILDING

146 parent meetings were organised by the projects, attended by 5139 parents
44 youth are actively representing their peers in the support group committees

INCLUSION

153 children gone to school as a result of proper continence management. More schools are being targeted in sensitization activities and are taking active part in the activities of our local partners. In total **226** schools are part of our local network







PREVENTION

Around **1 040 000** Folic Acid tablets were distributed to 15 585 women



2014 HIGHLIGHTS



JANUARY	FEBRUARY	MARCH	APRIL	MAY	JUNE
<p>IF supported IDDC European Elections Statement, "Putting People First - The European Union Acting to Strengthen the Voice of Persons with Disabilities Globally"</p>	<p> network</p>	<p>Together with the partners of Smarter Futures project (Ministry of Foreign Affairs of the Netherlands, Akzo Nobel, and Food Fortification Initiative) we published a guide for Fortification Monitoring and Surveillance called FORTIMAS</p>	<p> PUSH Alliance</p>	<p>IF President Margo Whiteford and former IF President Pierre Mertens established strong connections with the China Disabled Persons' Federation (CDPF) in an effort to raise awareness about SBH, remove stigma, and improve the access to healthcare for people with SBH in China. As a result, a special committee for Spina Bifida and Hydrocephalus has been established within the CDPF</p>	<p> international congress</p>
<p> participation</p>	<p>The establishment of IF Global Experts Network, chaired by the IF President, Margo Whiteford. Areas of work: Services and Care (Benjamin Warf), Human Rights (David Nolan Morrissey), Social Inclusion (Amy McPherson), Genetics (Richard H. Finnell), Causes (Anne Molloy) and Public Health (Klaus Kraemer)</p>	<p> monitoring tools</p>	<p>The first meeting of the PUSH Alliance took place in Boston. Organized by Boston Children's Hospital, IF and CDC's National Center on Birth Defects and Developmental Disabilities, it brought together representatives from 21 different organizations in academia, health services, private and public sectors, who discussed ways to address challenges, help advance research, and strengthen to move forward prevention and care efforts in the fields of Spina Bifida and Hydrocephalus</p>	<p> new organisations</p>	<p>IF's 25th International Spina Bifida & Hydrocephalus Congress: "GENERating Changes" aimed at refocusing on genetic factors as well as outlining and analysing factors that facilitate or hinder the full social inclusion of young persons and adults with SBH. The participants have also been reminded of the importance of folic acid and the need for both supplementation and fortification. Young people with SBH had the opportunity to discuss their life experiences and issues such as sexuality and employment. APEBI, the Argentinian Association for Spina Bifida, has recently initiated the creation of the LATAM Network on Spina Bifida and Hydrocephalus</p>

IF contributed to the development of the **UNICEF Study on Children with Disabilities Living in Uganda: Situational Analysis of the Rights of Children with Disabilities in Uganda**. The study revealed a gap in addressing the needs of children with disabilities by duty-bearers and key stakeholders. It used the example of IF's project aimed at improving quality of life for children with SBH in Uganda, undertaken with the lead of RHF - Norwegian Association for SBH



transition

Two projects related to **grain fortification** received the highest performance ranking possible in an evaluation of Schokland and Millennium Agreements. The Smarter Futures partnership for Africa and the Global Alliance for Improved Nutrition (GAIN) **Premix Facility** were among seven projects rated as having "very good overall performance" Increasing a population's vitamin and mineral intake by fortifying wheat and maize flour and rice increases productivity, improves children's cognitive development, and reduces the risk of neural tube birth defects such as spina bifida. Fortification also has economic consequences as a country benefits from increased productivity and averted healthcare costs



organisational support

On 20 November 2014, the **Universal Children's Day** and the 25th anniversary of the **UN Convention on the Rights of the Child**, a young boy with SBH from Slovakia addressed the three top EU institutions' representatives. He stressed the importance of working with and for children and young people with disabilities. Too many children still do not enjoy their full rights on par with their peers



human rights

JULY

AUGUST

SEPTEMBER

OCTOBER

NOVEMBER

DECEMBER



study on children

IF is organised a workshop in Kenya on **Preparing for adult life and development of adult services** via partnerships for managing the transition of people with SBH from paediatric to adult services. The overall aim was to facilitate the development of a model of service that addresses the changing healthcare needs of persons with childhood-onset disabilities as the individual grows from a child to youth, from youth to young adult, and from young adult to adult. On this occasion we developed a **guide on transition from childhood to adolescence** for people with Spina Bifida and Hydrocephalus in Africa



prevention

The new **Association for Spina Bifida and Hydrocephalus South Africa (ASBAH SA)** was launched in Cape Town. It will reach out to the different South African provinces and wants to develop, together with the South-African experts, a place where all persons with SBH would be able to receive the right support

25 October
World Spina Bifida and Hydrocephalus Day



rights of children

IF celebrated the **International Day of Persons with Disabilities**. Three young adults with spina bifida and hydrocephalus represented IF at the European Day of Persons with Disabilities in Brussels. Persons with disabilities, and especially young persons with disabilities, have the right to fully participate in society, and in equal terms with others. This right is enshrined in the UN Convention on the Rights of Persons with Disabilities

Launch of IF Strategic Plan
2015-2017

25 OCTOBER

WORLD SPINA BIFIDA AND HYDROCEPHALUS DAY

People with Spina Bifida and Hydrocephalus demand the realization of the right to health!

The World Spina Bifida and Hydrocephalus Day's third edition kicked- off with the theme "Access to Healthcare for all". It reminded the public and policy makers that Spina Bifida and Hydrocephalus are a reality and increased awareness to improve the lives of people living with these conditions while celebrating many achievements made by our enthusiastic worldwide community.

Persons with Spina Bifida and/or Hydrocephalus and their parents need healthcare and social services to coordinate and cooperate with each other, in order to deliver appropriate, timely, adequate and efficient treatment and support. Services provided at an affordable and accessible multidisciplinary clinic are the best way to treat, support, and follow up a person with SBH.

Health is a fundamental human right indispensable for the exercise of other human rights. The highest attainable standard of health is conducive to living an active life in dignity.

There are many social determinants of health, such as general socioeconomic, cultural and environmental conditions, living and working conditions, social and community influences, individual lifestyle factors, age, gender and hereditary factors.

The realization of the right to health therefore requires a multidisciplinary approach, from childhood into adulthood, and access to affordable, adequate, and appropriate services is imperative.

Health is a national responsibility and health systems vary greatly within the European Union and worldwide. Medical care, medical devices and medical supplies available to citizens in one EU Member State, or region within a EU Member State, may be inaccessible to others. These health inequalities create great obstacles to living an active life and to giving a meaningful contribution to society. This is especially true for people with disabilities with complex needs, such as people with Spina Bifida and Hydrocephalus, who still face exclusion from the healthcare system or who have difficulties finding access to the appropriate treatment and care.

For people with Spina Bifida and Hydrocephalus limited or inadequate access to healthcare can increase their marginalization in society and their risk of developing life threatening complications. Even though more people with Spina Bifida and Hydrocephalus reach adulthood, mortality levels remain high.

25 OCTOBER
WORLD
SPINA BIFIDA &
HYDROCEPHALUS
DAY





TURKEY



NIGERIA



ARGENTINA



BELGIUM



CHINA



SOUTH AFRICA



EASTERN UGANDA



GUATEMALA



Lo-Call 1800 20 22 60

World Spina Bifida
and Hydrocephalus Day

Background

In 2011, IFA's General Assembly designated 23 October as the third Spina Bifida and Hydrocephalus Day (3rd) and its member organisations including Ireland—Spina Bifida Hydrocephalus Ireland will use this day to raise awareness about Spina Bifida and Hydrocephalus and the ways in which neural tube defects (NTDs) can be prevented. As from 2012 the third Spina Bifida and Hydrocephalus Day is celebrated every year. The third Spina Bifida and Hydrocephalus Day, led by the International Federation for Spina Bifida and Hydrocephalus and its member associations (including Ireland), is an opportunity to raise awareness and understanding about Spina Bifida and Hydrocephalus. It is also a way to advocate and promote the rights of people with these impairments.

IRELAND



L'Acido folico è
un gesto semplice
che può cambiare
una vita

A.S.B.I.

ITALY



LITHUANIA



NORTHERN IRELAND



KENYA



NIGERIA



USA



SLOVAKIA



UK



NORWAY



UGANDA



With a Little Help From Our Friends

Friday 24th October - Sunday 2nd November

To coincide with World Spina Bifida and Hydrocephalus Day on 25th October 2014, we are running an intensive fundraising week 'With a Little Help from Our Friends' and are aiming to raise £10,000 in this area.

You can be the difference

Could you organise your own fundraising event during

SCOTLAND



SWEDEN



TANZANIA



POLAND



FINLAND

SEE MORE:

WWW.WORLDSPINABIFIDAANDHYDROCEPHALUSDAY.COM



WWW.PU-SH.ORG

PEOPLE UNITED FOR SPINA BIFIDA & HYDROCEPHALUS

CAMPAIGNS

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, whoever they are in the world, who are working towards improvement or to challenge injustice and inequality.

SOCIAL MEDIA

Through the PUSH online platform we 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 SBH
- forming networks of like-minded people to bring about change
- coming together to meet and support each other.

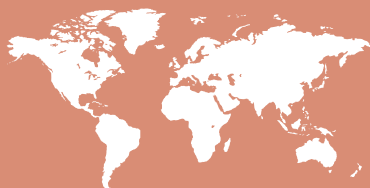
COMMUNITY

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

395 members



33 worldwide campaigns



1671 supporters



37%



63%

OUR EUROPEAN WORKSHOPS IN 2014

Download our Toolkits! ABC of Equality, Advocacy, and Communications



8-10 MAY 2014 BRATISLAVA, SLOVAKIA

“ABC OF EQUALITY: ADVOCATING FOR BETTER CARE”



16-17 OCTOBER 2014

DUBLIN, IRELAND “2ND S.H.A.P.E OUR FUTURE WORKSHOP”

SBHI CONFERENCE “MY SAY. MY WAY”



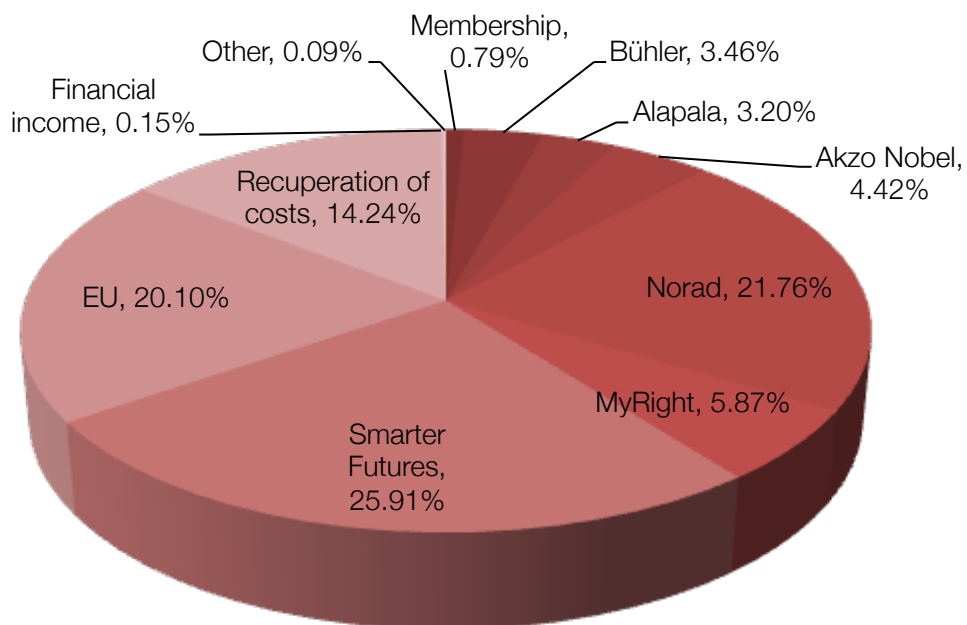
3-5 DECEMBER 2014 TALLINN, ESTONIA

2ND BALTIC CONFERENCE ON TREATMENT AND CARE FOR SBH PATIENTS – A PRACTICAL APPROACH

“3RD S.H.A.P.E. OUR FUTURE WORKSHOP”

FINANCES IN 2014

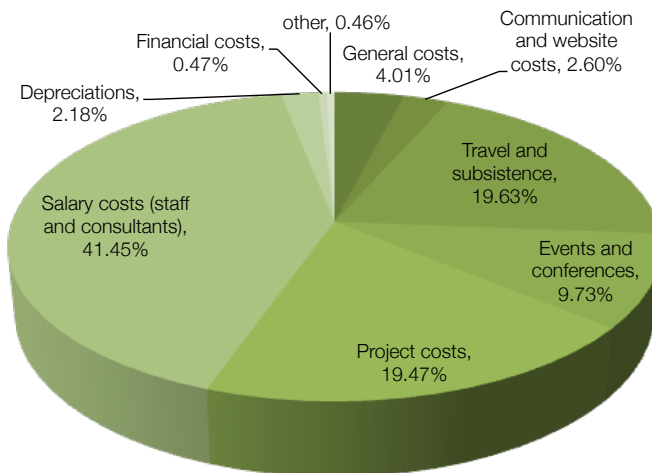
INCOME



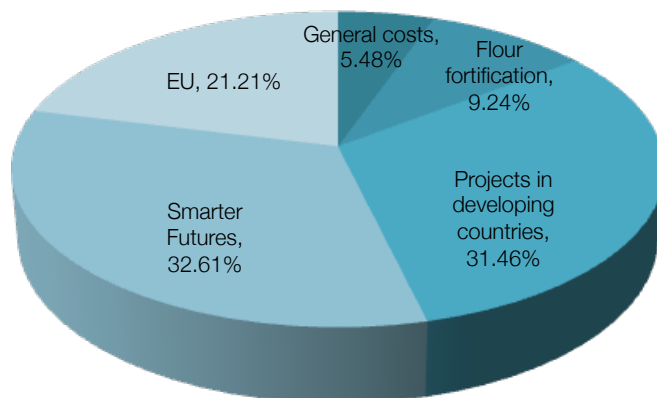
TOTAL INCOME

1.130.412 EURO

COSTS (BY TYPE)



COSTS (BY PROJECT)



TOTAL COSTS
1.125.668 EURO



THE INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

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