

15

ANNUAL REPORT



Working to reduce the incidence of spina bifida and hydrocephalus by primary prevention and to improve their quality of life.

MESSAGE FROM THE PRESIDENT

Dear friends,

2015 was a year of change for all of us. IF has been working hard to ensure that people with spina bifida and/or hydrocephalus (SBH) are well represented and their issues recognised internationally.

First and foremost, I would like to thank our members, partners and supporters. Reaching our objectives for the past year would not have been possible without you. Your involvement truly shows that you share our mission and make us want to advance in our work around the world to help people with SBH fully enjoy their rights. At the end of the year we welcomed six new member organisations and we have been active at international and regional levels providing our support and sharing good practices.

In 2015, we adopted a new strategic plan for 2015-2017. It has been a good opportunity for us to reevaluate our achievements, challenges and opportunities and to integrate them into a strategy that shapes our future actions.

IF is constantly evolving. The activities highlighted in this report are a testimony to the progress that has been made. New developments include the creation of the IF Youth Group; our involvement in ensuring that the particular needs and views of youth with SBH are recognised.

We have also initiated projects related to advance the greatest benefit to those affected by spina bifida and hydrocephalus through the PUSH! Global Alliance platform. It is of utmost importance that IF keeps its focus on both prevention and care, providing its expertise and guidance towards the improvement of the quality of life of people with SBH and their families in developed and in developing countries..

Finally, I thank the IF staff for their support during the past year and look forward to on-going productive cooperation in the future.

Margo Whiteford, IF President

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1. KEY FACTS



**“LIFETIME
ACHIEVEMENT
AWARD” FROM FEBHI**

Conference and workshops

The 26th International Conference on Spina Bifida and Hydrocephalus, Solbiate Olona

More than 100 participants

44 speakers



5 thematic Workshops, Solbiate Olona



EU Workshop, Vilnius

30 participants

4 World Cafés



EU Workshop, Solbiate Olona



Trainings

23 July: **Webinar on EU funds** with Alessandro Negro "EU FUNDS MAPPING Overview of European Funding Opportunities for IF Global and Members"

15 to 20 December: **Webinar on Social media**: part I with Tom Scott from the *Spina Bifida Hydrocephalus Scotland*

IF award 2015



IF President Margo Whiteford presented him with the award during the 26th International Conference on Spina Bifida and Hydrocephalus.

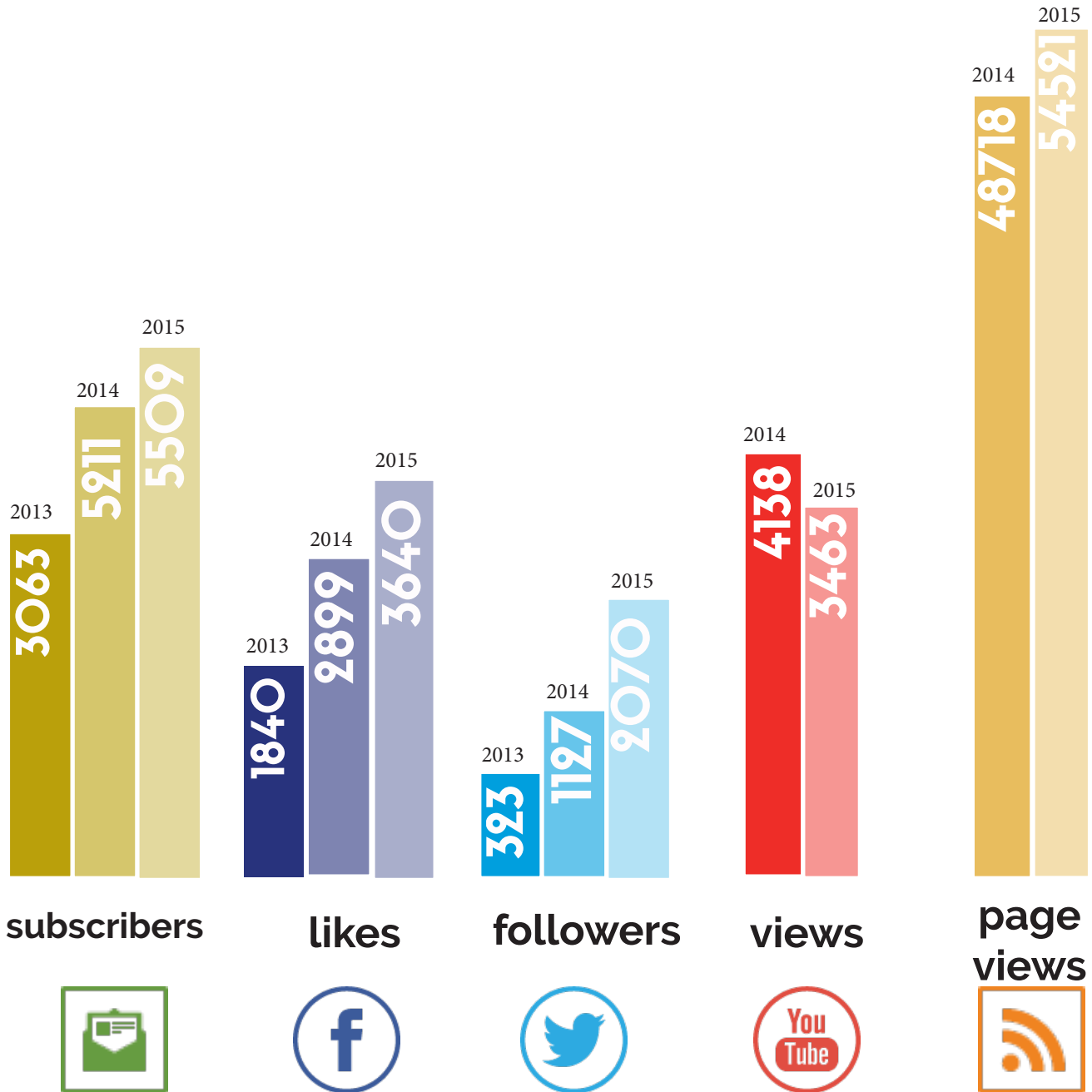
"I am very pleased and really honoured to receive this Award. It brings me to the beginning of my career when I was deeply involved in caring for children with congenital disabilities, including spina bifida and hydrocephalus. I am glad to receive this award for my current main interest: prevention of birth defects.. Last, but not least, I see this Award as an Award to the International Clearinghouse for Birth Defects Surveillance and Research, which was very active to organize and support training courses on surveillance of birth defects, particularly for developing countries." - Prof. Mastroiacovo

The 2015 recipient of the IF Annual Award was **Pierpaolo Mastroiacovo**, Professor of Pediatrics; Director of the Alessandra Lisi International Centre on Birth Defects and Prematurity (ICBD), and the Centre of the International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR).



The IF board decided to award **Prof. Mastroiacovo** in recognition of his **outstanding career** and his **significant contribution to the prevention of birth defects.**

Our online audience/outreach





Scotland



Argentina

Spain/Catalonia

Italy

25 OCTOBER WORLD SPINA BIFIDA & HYDROCEPHALUS DAY



25 October is **World Spina Bifida and Hydrocephalus Day** to raise awareness about SBH and to advocate and promote the rights of persons living with these conditions.

This year, the day had special significance because it was the first following the adoption of the UN Committee on the Rights of Persons with Disabilities (UNCPRD) final recommendations to the EU, September 2015, and the adoption of the new Agenda for Sustainable Development Goals (SDGs), October 2015, the most inclusive for people with disabilities. The SDGs emphasise the inclusion and participation of persons with disabilities as one of the keys to end poverty and discrimination.

Persons with SBH continue being denied information about treatments, are financially discriminated when travelling across EU borders in search of better healthcare, and have difficulties finding access to the appropriate treatment and care.

Nigeria



Belgium



Uganda



South Africa

SPINA BIFIDA & HYDROCEPHALUS I

25th October.

Good Nutrition and Folic Acid Prevents Spina



Kenya

World Spina Bifida and Hydrocephalus Day

This Sunday, to show our intent to spread awareness more effectively every single day, Spina Bifida Hydrocephalus Ireland (SBHI) will officially launch a new, refreshed logo and, later in the week, a wonderful new website!

All will be revealed here on Facebook, so watch this (web) space!



Ireland

octubre 25 la mundial

Espina Bifida

La Fundación Mónica Uribe Por Amor conmemorará este día brindando información acerca de su prevención este **viernes 23 de octubre** en diferentes puntos de la ciudad.

¡Te esperamos!



Colombia



Lithuania

IX JORNADAS DE ANSES
CRECIENDO EN CALIDAD DE VIDA



Sábado 24 de octubre de 2015
10:00 a 18:00

Centro de Estudios Múltiple Alina Koplowitz
Bulevar José Prat, 42
Villaverde (A. Madrid)

Spain/Madrid

Shine
New York - Birmingham - London - Manchester - Madrid

This week is Spina Bifida and Hydrocephalus Awareness Week

So Shine is celebrating its work with its members and supporters throughout England, Wales and Northern Ireland...

"Shine has put us in touch with lots of other people and families living with spina bifida and hydrocephalus. We feel a part of a very special and unique community that have given us lots of love, support, advice and most importantly, hope and inspiration for our daughter's future."

If you would like to support Shine's ongoing work, please text AWWK15 £3 to 70070

A big 'thank you' from everyone at Shine for your generosity

© Shine, Page No: 2193231

United Kingdom



Sudan



Landelijke dag Spina Bifida Hydrocephalus

Zaterdag 24 oktober: landelijke dag Spina Bifida Hydrocephalus voor ouders met hun kinderen, grootouders, volwassenen & partners, professionals

BOEKEL - BY BOEK

The Netherlands



Spain/Navarra



Sweden



Bulgaria

2. ABOUT US, MISSION AND VALUES



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.

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.

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 spina bifida and hydrocephalus, and celebrates their contribution in all areas of life.

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.

OUR BOARD 2015-2016



Margo Whiteford
President
Scotland



Thelma Cloake,
secretary,
Ireland



Cato Lie,
Treasurer,
Norway



Lumbwe
Chiwele,
Zambia



Santosh
Karmarkar,
India



František
Horn,
Slovakia



Emine Nurdan
Anli, Turkey



Emma
Suardiaz,
Spain



Elena Zappoli,
Argentina

OUR SECRETARIAT

- Lieven Bauwens: Secretary General
- Janina Arsenjeva, Europe Programme Manager
- Jana Moravcova: Advocacy Officer
- Jackie Bland: Development Director
- Renée Jopp: Information Officer
- Ewa Kampelmann, Marta Anguera: Communications Officers
- Anna Maarit Paakkulainen/ Margo Vandenbroucke : PA /Administrator
- Katalijne Van Diest: Programme Manager, International Solidarity
- Martine Austin: Programme Manager - Global Prevention
- Anna Verster: Senior Advisor, Food Fortification

Communication trainee 2015: Inma López

IF volunteers in 2015: Eric Holdtgrefe, Vera Costa

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.

IF is **member of:**

- European Disability Forum (EDF)
- European Patients Forum (EPF)
- Eurordis
- The International Disability Alliance (IDA)
- International Disability and Development Consortium (IDDC)

In 2015 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)
- European Patients' Forum (EPF)
- 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

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 our Global Experts Panel.

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

Composition of the **Global Experts Network**:

- **Femke Bannink**, Senior Advisor/ Researcher
- **Richard Bransford**, general surgeon, MD, FACS
- **Myleen Christiaens**, consultant on Spina Bifida
- **Filippo Ciantia**, tropical medicine,
- **Kordelia Fischer-Borchert**, consultant, community-based rehabilitation
- **Philippe Gillis**, consultant paediatrics and tropical medicine
- **Helen Healy**, consultant life skills and transition
- **Bo Hjelt**, consultant fundraising and general management

- **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

Global liaisons:

- **Marisol Hernandez**, IF liaison in Buenos Aires
- **Liu Jiarong**, IF liaison in Beijing

FFI Consultants:

- **Ronald Afidra**, FFI Africa Network Coordinator
- **Quentin Johnson**, FFI Training and Technical Support Coordinator



IF CALENDAR

JANUARY	FEBRUARY	MARCH	APRIL
<p>PUSH Executive Committee meeting, Boston</p>	<p>ICBDSR/CDC/WHO Training on Birth Defect Surveillance</p>	<p>World Birth Defects Day (3 March)</p> <p>Face-to-face meeting of IF's Global Experts Panel</p>	<p>FFI EMT meeting</p> <p>Working group International Solidarity</p> <p>EU High Level Group on Disability</p>
MAY	JUNE	JULY	AUGUST
<p>QA/QC workshop in Harare, Zimbabwe</p> <p>Launch of the G4 Alliance</p> <p>Mission to Sudan</p>	<p>FEBHI rewards IF with its "Lifetime Achievement Award"</p> <p>EDD 2015</p> <p>COSP CRPD</p>	<p>Webinar on EU funds</p> <p>SRSBH conference</p> <p>IF Board meeting EU workshop, Vilnius</p>	<p>Configuration of the IF Youth Group</p> <p>Response to the list of issues on the European Union Report to the UNCRPD</p>
SEPTEMBER	OCTOBER	NOVEMBER	DECEMBER
<p>Global Fortification Summit, Arusha, Tanzania</p> <p>International Conference on Birth Defects</p>	<p>26th International conference & EU workshp, Solbiate Olona</p> <p>IF Board meeting</p> <p>WSBH day (25 Oct)</p> <p>3rd Global Experts Panel meeting</p>	<p>IF's Annual African workshop "Lifelong care" in Lusaka, Zambia</p> <p>FFI EMT meeting</p>	<p>Webinar on Social Media: part I</p> <p>FFI/IF mission to China</p>

3. WIDENING OUR NETWORK



57 MEMBERS



**6 NEW MEMBERS
IN 2015**

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 - **China** China Association of Persons with physical Disabilities (CAPPD) - **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-liittory - **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) - **Latvia** Latvijas spina bifida un hidrocefālijas biedrība (LSBH) - **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 Bifida Foundation "Maral Angel" - **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" - **Portugal** Associação e 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 Hydrocephalus association of Serbia **Slovakia** Slovenská spoločnosť pre Spina Bifida a/ alebo Hydrocephalus, o. z. - **South Africa** Association for Spina Bifida and Hydrocephalus - South Africa (ASBAH-SA) - **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) Asociación Murciana de padres con hijos de Espina Bífida e Hidrocefalia (AMUPHEB) - **Sudan** Spina Bifida Federal Association - **Sweden** RBU, Spin-Off - **Switzerland** Schweizerische Vereinigung zugunsten von Personen mit Spina Bifida und Hydrocephalus (SBH) - **Tanzania** Association for Spina Bifida and Hydrocephalus Tanzania (ASBAHT) - **Turkey** Türkiye Spina Bifida Derneni - **Uganda** Central Uganda Spina Bifida and Hydrocephalus Network - **UK** SHINE - **USA** Spina Bifida Association of America (SBAA); Hydrocephalus Association; Pediatric Hydrocephalus Foundation

4. INTERNATIONAL DEVELOPMENT



2940 NEW
CHILDREN JOIN
SHIP



4585
SHUNTS

Children in follow up

26.116 children being followed in their rehabilitation and development

417 home visits conducted and 810 children visited

Treatment

3020 joined the programmes in 14 countries

873 ETV operations performed in Mbale, OURS, Katalemwa, Kenya, Blantyre

Training

57 trainings continence management organised

141 staff trained

4.641 participants in parent meetings

19 trainings staff with 141 participants

Prevention

1.091.408 folic acid tablets distributed

48 trainings organised on prevention with 2016 participants

Youth programme

23 youth meetings and 181 participants

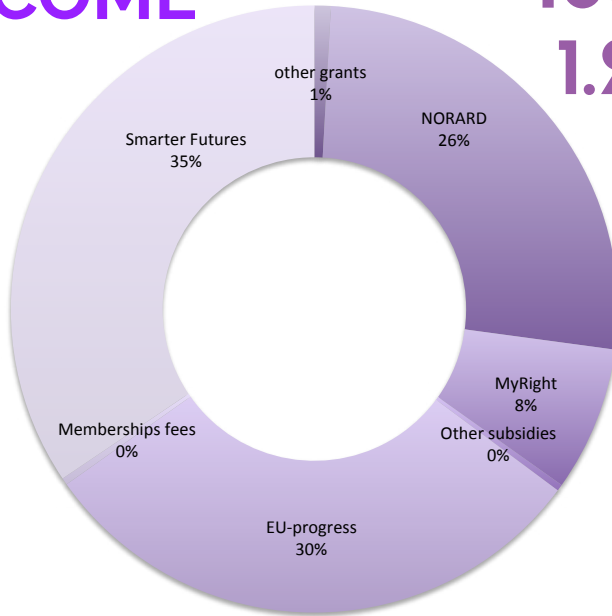
18 youth as a trainer from OURS, Katalemwa, Kenya, Moshi, Khartoum, Zambia and PASHL

26 youth active in committees

A close-up photograph of a white sheet of graph paper with a blue line graph. The graph shows a line that starts at the top left, moves down with several small peaks and valleys, and then continues to move down towards the bottom right. To the right of the graph, there are three stacks of gold coins. The top stack is the tallest, followed by a shorter one, and then a third one that is partially obscured. The background is a light blue gradient.

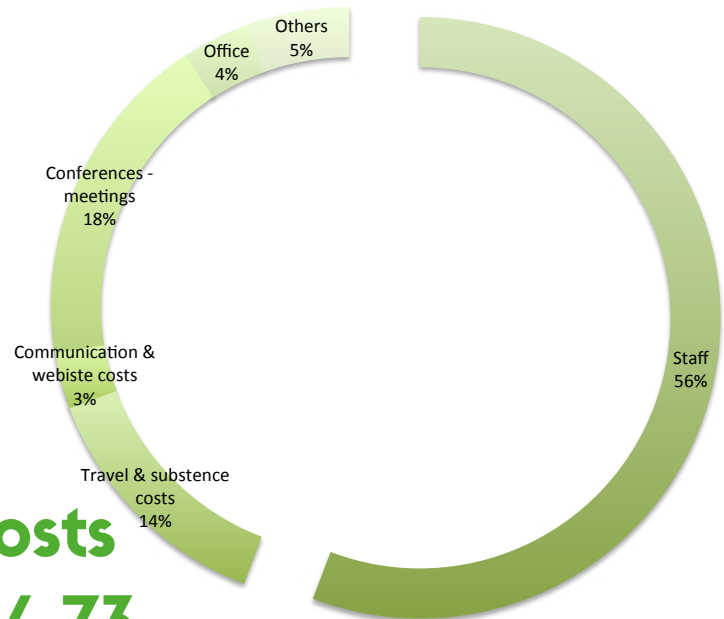
5. IF IN NUMBERS

INCOME



Total income
1.297.362,93

COSTS



Total costs
1.287.664,73



The International Federation
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