



**INTERNATIONAL FEDERATION
FOR SPINA BIFIDA AND HYDROCEPHALUS**

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

Media Release

FROM THE NEW LATAM NETWORK FOR SPINA BIFIDA AND HYDROCEPHALUS: GENETIC FACTORS AND SOCIAL INCLUSION ARE FUNDAMENTAL WORLDWIDE!

6-7 June 2014 // During last two days Buenos Aires was filled with discussions on key topics for the Spina Bifida and Hydrocephalus (SBH) global community. Genetic factors of SBH, social inclusion, and the right to health were at the top of the agenda. Around 400 participants attended IF's 25th International Spina Bifida & Hydrocephalus Congress: "GENERating Changes" and more than 200 people followed online. IF's global network has been enlarged by welcoming six new organisations.

Approximately 300.000 people worldwide are born with Neural Tube Defects (NTDs) like Spina Bifida. Being one of the preventable health conditions, it still affects approximately 1 in every 1000 pregnancies a year. Bearing in mind the importance of folic acid in NTD prevention as well as advancements in fetal surgery, neurosurgery, urology, and neuro-orthopaedics, **IF's congress 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.** Invited experts analysed several issues ranging from scientific breakthroughs to social inclusion, education, access to healthcare, adaptive sports, and labour market insertion.

"The IF Annual Conference arranged by APEBI in Argentina has had something for everyone: a wonderful opening ceremony with young representatives carrying flags, police band and a tango concert. The session on the medical aspects of SBH have been very interesting giving the recent updates on situating regarding fetal surgery around the world.

There have been many presentations tackling social inclusion and the barriers to the full involvement of PWD in society. 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. All in all, a very successful conference!" said **Margo Whiteford**, IF President.

APEBI, the Argentinian Association for Spina Bifida, has recently initiated the creation of the LATAM Network on Spina Bifida and Hydrocephalus. The newly created LATAM Network on SBH comes in line with the launch of the PUSH campaigning platform in Spanish. It will facilitate the creation of campaigns by Spanish speaking individuals or organisations willing to communicate what they stand for and connect with others sharing their cause.

The IF Award 2014 was given to a paediatric surgeon Dr. Santiago Portillo as an appreciation of his professional expertise and remarkable achievements in the treatment of SBH and his personal commitment and dedication to his daily work.



**INTERNATIONAL FEDERATION
FOR SPINA BIFIDA AND HYDROCEPHALUS**

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

*“The positive value of the international congresses like today’s is undoubtful. It was well attended by the Latin American associations’ representatives, families, doctors, and international experts. It shows the importance of addressing topics so common to the international audience. Spina bifida is the second cause of child mortality in Argentina. We are doing our best to enhance the visibility of spina bifida and hydrocephalus globally within the medical community, government, civil society and private sector in order to influence policy makers to assure better quality of healthcare services worldwide” stated **Lieven Bauwens**, IF Secretary General.*

Our international network has significantly expanded by welcoming 6 new members from:

- Hungary: [Spina Bifida and Hydrocephalus section of MEOSZ](#)
- Sweden: [Spin-Off](#)
- Mongolia: [Mongolian Spina Bifida Foundation “Maral Angel”](#)
- Uganda: [Central Uganda Spina Bifida and Hydrocephalus Network](#)
- USA: [Hydrocephalus Association](#)
- USA: [Pediatric Hydrocephalus Foundation](#)

Contact:

Ewa Kampelmann
Communication Officer
IF - International Federation For Spina Bifida & Hydrocephalus
Cellebroersstraat 16
B- 1000 Brussels
T:+32 (0) 25 02 04 13
ewa.kampelmann@ifglobal.org

The International Federation for Spina Bifida and Hydrocephalus (IF) is the worldwide umbrella organisation for Spina Bifida and Hydrocephalus organisations. It was created in 1979 by national organisations of people with these impairments and their parents. Today IF's members consist of 57 regional and national umbrella organisations for Spina Bifida and Hydrocephalus spread over five continents.

The mission of IF is to improve the quality of life of people with Spina Bifida and Hydrocephalus throughout the world and to decrease the prevalence of Spina Bifida and Hydrocephalus by primary prevention. In its work, IF focuses on four main domains; Prevention, International Solidarity, Human Rights and Network Development. More information on: www.ifglobal.org