



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*

Press Release

PU-SH.org campaigning community goes live today!

25 October 2013 /// To mark the second edition of the World Spina Bifida and Hydrocephalus Day, the International Federation for Spina Bifida and Hydrocephalus launches PUSH! - the brand new online campaigning community of People United for Spina Bifida and Hydrocephalus.

The idea of PUSH was born as a group of people within IF considered what could be done so that people with spina bifida and hydrocephalus could have a greater visibility and impact throughout the world.

We are aware of enormous challenges and issues faced by all those whose lives are affected. 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 stories of high numbers of children with hydrocephalus left untreated. The difficulties faced by countries in Eastern Europe in getting even the most basic continence management products. 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. The transition period is now high on the agenda of Scandinavian countries, but remains a challenge for the other parts of Europe. 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.**”* said Margo Whiteford, IF President

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.

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.



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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 can 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.

Being a member of PUSH means:

- to immediately become a member of the first global community of people affected by sb/h;
- to be able to access members of the PUSH community as it grows to find out where there are people who share one's concerns/life experience;
- to be invited to push for campaigns and policies designed to improve life of people with sb/h around the world.

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The International Federation for Spina Bifida and Hydrocephalus (IF) is the world-wide umbrella organisation (INGO) 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 46 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 is focusing in four main domains; Prevention, International Solidarity, Human Rights and Network Development. More information on: www.ifglobal.org