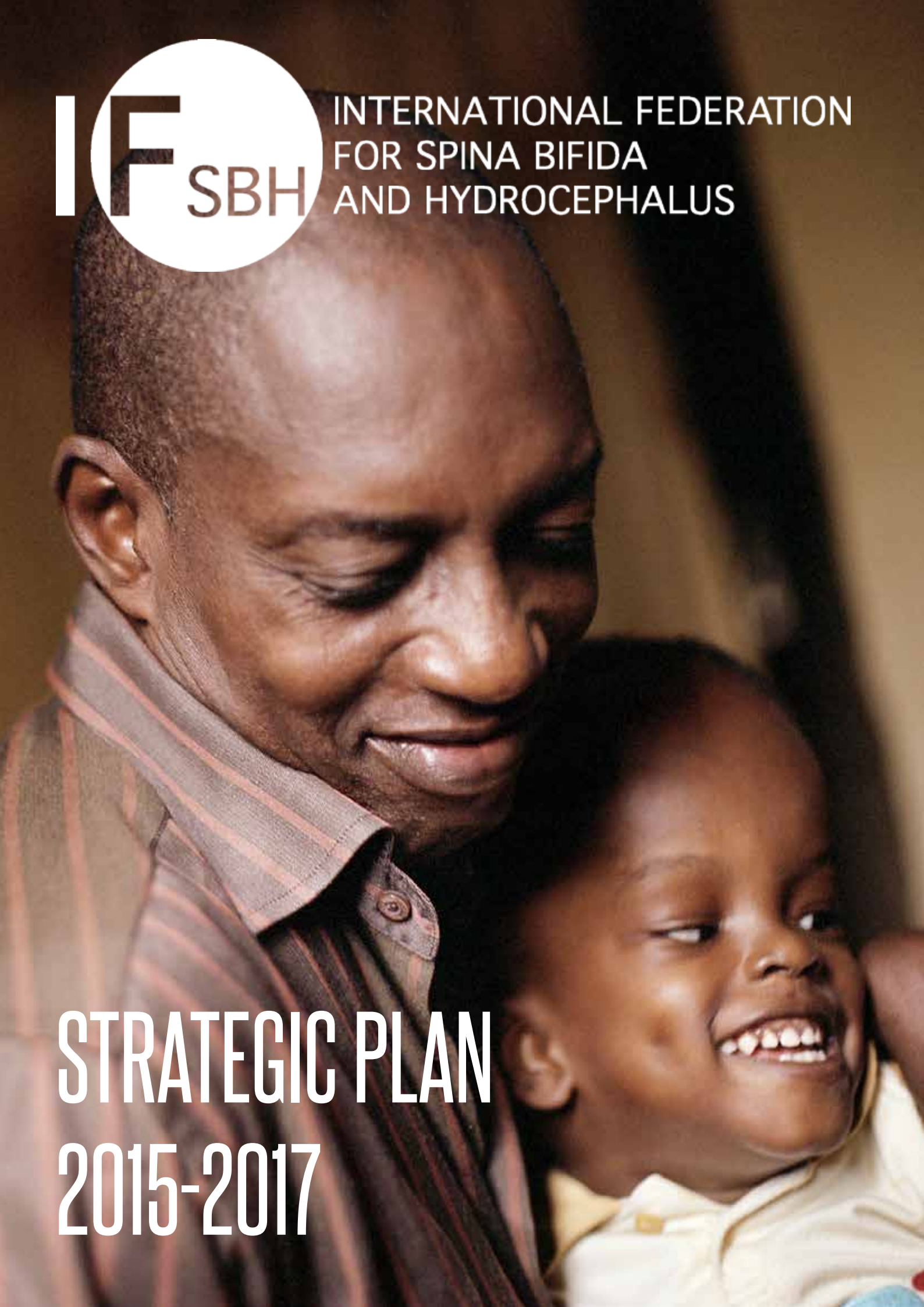




INTERNATIONAL FEDERATION
FOR SPINA BIFIDA
AND HYDROCEPHALUS

STRATEGIC PLAN
2015-2017



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IF MEMBERS

Advocating
Convening
Building Capacity

SETTING

THE SCENE



IF, its members and supporters

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 Expert Panel (GEP)** and its Network. The Network is a multidisciplinary scientific advisory body to IF Board of directors. 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 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. Formal launch of the PUSH Alliance is planned for 2015.

Our focus areas

IF's reason for existence is to support people with SBH and their families, advance the research into causes of SBH, increase primary prevention and influence the decisions that affect people with SBH.

1. **Neural tube defects (NTDs)**, one of the most common birth defects, affect an estimated 320,000 newborns a year worldwide. Though the causes of NTDs are not fully understood, studies have shown that daily intake of 400 mcg folic acid during the periconceptional period significantly decreases the risk of NTDs. Fortifying food with low levels of folic acid and taking supplements are low-cost, effective means for reducing the risk of NTDs, particularly in cases of unplanned pregnancies. These measures are also significantly less painful and traumatic than termination of pregnancy often practices when the fetus has been diagnosed with SBH. Therefore, IF supports the **primary prevention of NTDs** through food fortification and folic acid supplementation.

2. Newborns with SBH are still withheld treatment in many parts of the world, owing to lack of access to quality healthcare and services. Many of them die unnecessarily or continue to live but not thrive in inhumane circumstances.

The right to health and access to healthcare continues to be of great importance for people with SBH throughout their lifespan. Inadequate healthcare puts people at higher risk of secondary disabilities, chronic health conditions and premature death. Therefore, the quality of healthcare they receive is the determining factor of people's ability to enjoy all other human rights.

3. IF recognises that the objective to improve people's enjoyment of the right to health is not possible without strong leadership of people with SBH at the national, regional and local levels. Therefore, **expanding its membership and supporting its existing members** remains the most significant organisational priority for IF. In addition to its importance to internal IF functioning, it supports the building of the global community of people with SBH and their families and supporters.

IF's work lies at the intersection of disability and health in that it provides unique expertise in the enjoyment of the right to health by people with disabilities.

Whereas many other organisations of disabled people promote the rights of persons with disabilities, and many other NGOs are engaged in the health discourse,

IF brings together these two distinct but closely related fields. Naturally, children and adults with SBH face the same challenges in their lives as people with other disabilities, such as discrimination in access to services, education or employment, inaccessibility, poverty, etc.

Since these issues are not unique to people with SBH, they are best approached through cooperation with partners, such as the European Disability Forum (EDF), International Disability and Development Consortium (IDDC) and International Disability Alliance (IDA).

The distinct dimension of the SBH discourse is the **right to health and access to healthcare**.

“3. The Human Rights Council calls upon States to adopt a human rights-based approach to reduce and eliminate preventable mortality and morbidity of children under 5 years of age, including in scaling up efforts to achieve integrated management of quality maternal, newborn and child health care and services, particularly at the community and family levels, and to take action to address the main causes of preventable mortality and morbidity of children under 5 years of age.”

Human Rights Council Resolution A/HRC/27/L.23

“Preventable mortality and morbidity of children under 5 years of age as a human rights concern”

Political, economic, social and technological analysis

Politically, it is an opportune time to work on promotion of the rights of people with disabilities, including SBH. The adoption of the **UN Convention on the Rights of Persons with Disabilities (CRPD)** and the accompanying international, regional and national processes have put disability in the spotlight of many decision-makers and donors. This has been helped by the growing emancipation of the organisations of persons with disabilities and the calls to up the efforts to meet the **Millennium Development Goals** to prepare ground for the post-2015 global development process.

The **WHO 2014-2021 Disability Action Plan** provides opportunity to include the disability discourse in the health agenda and to improve access to all health services for persons with disabilities. The adoption of the WHO Resolution on birth defects urges WHO Member States to raise awareness about birth defects, to foster the development of parent-patient organizations, and to support families of children with birth defects and associated disabilities. Focus on **nutrition security** increasingly present in political agendas, particularly in developing countries. Most national strategies to combat malnutrition include a component of fortification of staple foods with folic acid, among other micronutrients.

At the same time, growing social and financial instability as the result of the **2008 economic crisis**, armed conflicts and the rise of global inequalities are making the promotion of solidarity-based social values challenging. The increase in the demand for high quality rights-based services for children and adults with disabilities has not been accompanied with the increase in spending. On the contrary, the **stagnation of healthcare and social reforms**, difficulties in accessing resources and unfavourable working conditions of grassroot activist associations are widely reported.

The increased vulnerability of people with disabilities in access to healthcare has been documented by the **EU Agency for Fundamental Rights in 2013**. Its findings corroborate the **2011 WHO World Report on Disability**, as well as IF's own 2013 findings. The **UNICEF State of the World's Children 2013** report also states that children with disabilities grow up poorer and have less access to health-care services.

The world continues to experience dramatic **technology innovation** and changes which affects every dimension of human and organisational behaviour and activities. Increasingly, social media is transforming not just how people connect and stay in touch, but also how they collaborate, plan, share information and make decisions.

SWOT ANALYSIS

STRENGTHS

- First-hand access to grassroots-level information through members
- Good network of supporters: medical experts, universities, public bodies
- Full membership EDF, IDDC and EURORDIS
- Long-established cooperation with the EU, WHO, UNICEF, Food Fortification Initiative, Centers for Disease Control and Prevention
- Multifaceted activities: advocacy, service provision, networking platform
- Entrepreneurial spirit

OPPORTUNITIES

- Commitment to realisation of CRPD rights
- WHO Disability Action Plan 2014-2021
- WHO 2010 Resolution on Birth Defects
- Post-2015 global development agenda
- Global momentum on nutrition security
- Pending membership application at International Disability Alliance
- Involvement of high-level external experts
- Ongoing development of the global alliance of likely-minded stakeholders on SBH

WEAKNESSES

- Members' limited capacity to actively engage
- Diversity of membership makes it difficult to find common issues to work on
- Knowledge is not concentrated in one source but spread across actors and continents
- Small secretariat, where specific knowledge resides with one staff whose absence creates a hiatus; conflicting priorities; high workload
- Limited unrestricted funding, not allowing for large changes in strategy

THREATS

- Very low visibility of disabilities IF works on (hidden, high mortality in developing countries)
- Very strong cultural stigma
- Crisis underfunds member and partner organisations
- Tendency to form large groups where the specificity of different disabilities is disappearing



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.

HOW DO

WE

REALISE

OUR

MISSION?



STREATEGIC OBJECTIVES

In 2015 – 2017, the three strategic objectives of IF are:

1. PRIMARY PREVENTION

Prevention of neural tube defects and hydrocephalus is improved globally.

National decision-makers better understand cost-effectiveness of primary prevention and take measure to increase public awareness about it.

National folic acid fortification strategies are adopted in cooperation with the public and private stakeholders.

IF gains more insight in the prevention of acquired hydrocephalus.

2. RIGHT TO HEALTH

Children and adults with spina bifida and hydrocephalus enjoy timely access to appropriate and affordable healthcare and rehabilitation of high quality without discrimination or prejudice.

Information about the rights of children and adults with SBH in healthcare is widely available for people with SBH and their families, medical and para-medical professionals and political decision-makers in appropriate and accessible formats.

3. COMMUNITY BUILDING

National associations of SBH feel the ownership of IF and feel empowered to advocate for full respect of human rights of people with SBH, and to provide their members with high-quality support.

More children and adults with SBH feel part of a global community that also includes researchers, healthcare professionals and everyone with an interest in SBH.

Our strategic objectives will be addressed through five interrelated channels:

Improving **knowledge** about spina bifida and hydrocephalus and people living with this disability. “Knowledge is the key to a better life” has been IF’s motto since 2002. It is understood that access to the latest, objective and transparent knowledge is the basis for formulating future strategies of action.

Improving internal and external **processes**. Sustainable, democratic and inclusive processes are equally important for improving the capacity of IF members, and for ensuring the consistent inclusion of the rights of people with SBH in legislative, policy and funding decisions on all levels.

Facilitating **learning and exchange**. The experience has shown that there is a wealth of experiences on good approaches to ensure human rights of people with SBH, particularly, the right to health. There is a burning need to provide a platform where these experiences – both national and international – are shared, disseminated and advanced.

Leading **political advocacy**. Professional research-based advocacy at local, national, European and international levels is key to achieving sustainable change and ensuring the respect of the right to health and other human rights of children and adults with SBH.

Campaigning and communicating outcomes. Strong communication, particularly using the opportunities offered by the social media, is important to building the community of people and celebrating their achievements.

STRATEGIC

OBJECTIVES

UNWRAPPED



STRATEGIC OBJECTIVE I: PRIMARY PREVENTION



PRIMARY PREVENTION of neural tube defects and hydrocephalus is improved globally. National decision-makers better understand cost-effectiveness of primary prevention and take measure to increase public awareness about it. National folic acid fortification strategies are adopted in cooperation with the public and private stakeholders. IF gains more insight in the prevention of acquired hydrocephalus.

We will contribute to improving primary prevention efforts through:

- 1. Improving national decision-makers' access to knowledge about primary prevention of spina bifida and adult hydrocephalus.**
In cooperation with research institutions and partners, IF will use the available research to convince the national authorities about primary prevention as the most efficient, cost-effective and safe way to reduce the incidence of spina bifida and hydrocephalus. Collected through collaboration with PUSH Alliance, the knowledge will be disseminated through bilateral exchanges, letters, social media, annual conference and other means. IF will also work towards better understanding on non-spina bifida related hydrocephalus.
- 2. Improving organisational capacity of IF members to work on primary prevention.**
Some IF members already do community awareness campaigns and political advocacy on primary prevention. IF will rely on their experience to support other members who interested in working on primary prevention. IF will multiply the effects of its members' work by teaming up with other stakeholders and relying on the support of its Global Expert Panel.
- 3. Facilitating mutual learning among IF members.**
IF will provide its members with a platform to exchange experiences and best national practices on successful primary prevention strategies.
- 4. Helping members develop research-based advocacy strategies and supporting them in the implementation of their advocacy goals.**
IF members who prioritise primary prevention as their advocacy objective will be supported by IF in drafting and implementing their strategies. IF will play the role of the multiplier of the national activities, provide expertise and link its members to other relevant initiatives. It is expected that at least five more countries will introduce mandatory food fortification strategies by 2017.
- 5. Supporting national campaigns and communicating outcomes.**
IF members who prioritise primary prevention will be provided with campaign support. They will receive training in using the PUSH platform to campaign, formulate messages and use social media. IF will step up its efforts to communicate the human rights approach to primary prevention and explore joint activities with partners working on reproductive rights and children's rights.

STREATEGIC OBJECTIVE II: RIGHT TO HEALTH



RIGHT TO HEALTH – children and adults with spina bifida and hydrocephalus enjoy timely access to appropriate and affordable healthcare of high quality without discrimination or prejudice. Information about the rights of children and adults with SBH to healthcare is widely available for people with SBH and their families, medical and para-medical professionals and political decision-makers in appropriate and accessible formats.

We will contribute to improving right to health through:

1. Improving the knowledge of external stakeholders about the causes of SBH and the solutions necessary to guarantee people with SBH full enjoyment of their human rights.

IF will develop accessible tailor-made materials targeting different audiences to explain the specific application of the right to health to people with SBH. These materials will serve the basis of our advocacy and be broadly disseminated. IF will increase the representational function of the Global Experts' Panel. In developing countries, IF will organize regular trainings for health professionals in and provide them with direct support.

2. Reinforcing IF presence and capacity to defend the rights of persons with SBH at all relevant regional and international fora.

IF will optimise its internal processes to ensure its continuous and proactive presence at international (WHO, OHCHR, UNCRPD Committee) and regional (EU) platforms. This will include increased networking channels, improved procedures for representation and position-taking, and better communication.

3. Uniting forces with other stakeholders and learning from their experiences.

IF will seek partnerships with likely-minded organisations. It will consider conducting joint activities compile good practices in an accessible and easy-to-use format. IF will particularly capitalise on its membership at the newly created PUSH Alliance, IDDC, FFI, EDF and EURORDIS.

4. Engaging in political advocacy on the issue of health as human right at all levels.

IF will explore the opportunities to influence the implementation of the WHO Global Disability Action Plan 2014 – 2021 and the WHO 2010 resolution on birth defects; achieve progress in the area of standards of neonatal care; and be involved in the formulation of future international and regional health policies. Building coalitions with other non-governmental organisations will be preferred to individual efforts.

5. Campaigning – how all the above frames the Right to Health campaign.

The 'Right to Health' campaign will be a continuation of ongoing research in the situation of IF members. The objective of the campaign is to raise global awareness of hidden problems of people with SBH and show positive solutions. Our aim is to make local actors and organisations more visible, shift the focus away from the narrative of suffering and highlight the community efforts to improve the lives of persons with SBH. Our accessible and well-connected online platform will serve as a tool to engage and inform the general public.

STREATEGIC OBJECTIVE III: COMMUNITY BUILDING



COMMUNITY BUILDING – National associations of SBH feel the ownership of IF and feel empowered to advocate for full respect of human rights of people with SBH, and to provide their members with high-quality support. More children and adults with SBH feel part of a global community that also includes researchers, healthcare professionals and everyone with an interest in SBH.

We will contribute to building a strong community of people with SBH and their families and supporters through:

- 1. Improving their access to knowledge about their human rights, and by sharing examples of the abilities and achievements of people with SBH.**
The wealth of knowledge about rights of people with SBH will be made available to the global community through IF's communication channels, analytical materials and events. IF will continue its collaboration with the visual artists to photograph the lives of ordinary people with SBH and highlight their contribution to the society.
- 2. Improving organisational capacity of IF members to function as representatives and defenders of children and adults of people with SBH in their community.**
Experience shows that IF members' limited capacity prevents them from setting ambitious objectives. IF will address this by (1) facilitating training and exchange activities to improve members' organisational skills; (2) support the work of its Youth advisory group to cultivate leadership skills of young people with SBH; and (3) offering experience placements at the IF office to representatives of its members. IF will continue supporting new SBH associations and extending its global representation.
- 3. Organising mutual exchange and learning activities on best practices in relation to the issues of interest to its members.**
IF members unanimously agree about the usefulness of learning from each other, including through exchanges between members from industrialised and developing countries. IF will facilitate this exchange and document the outcomes to consolidate and preserve the knowledge. The exchange activities will be both web-based and face-to-face. A members-only newsletter will serve as a platform for members to share their practices and seek partners for their work.
- 4. Helping members develop research-based advocacy strategies and supporting them in the implementation of their advocacy goals.**
IF members have expressed frustration at the slow pace of progress and the reluctance of the decision-makers to listen to them. IF will facilitate professionalization of its members' advocacy work through research assistance, political support and linking national processes to international and regional dynamics. Particular attention will be given to the universal application of the CRPD and coalition-building with likely-minded stakeholders.
- 5. Supporting IF members in designing and implementing campaigns.**
Professional campaigning is often underused by IF members due to lack of knowledge and capacity. Building on the four above sub-objectives, IF will provide continuous training in campaigning skills. Members will be provided with practical knowledge to design relevant campaigns and communicate smartly. IF's innovative online platform will provide an opportunity for a broader international reach of campaigns.

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 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
- **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 (SHAK)
- **Lithuania** Spina Bifida ir Hidrocefalija asociacija
- **Luxembourg** Association pour le Spina Bifida a.s.b.l.
- **Mexico** Asociación Mexicana de Espina Bifida 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"; Stowarzyszenie Chorych z Przepuklina Oponowo-Rdzeniowa R.P. (ASBP)
- **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 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, Spin-Off
- **Switzerland** Schweizerische Vereinigung zugunsten von Personen mit Spina Bifida und Hydrocephalus (SBH)
- **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



The International Federation for Spina Bifida and Hydrocephalus

Cellebroersstraat 16 - 1000 Brussels, Belgium

T: +32 (0) 2 502 04 13 F: +32 (0) 2 502 11 29

www.worldspinabifidahydrocephalusday.com

www.ifglobal.org

www.pu-sh.org

info@ifglobal.org

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