



**BECOME A MEMBER**



# IF MEMBERSHIP GUIDE 2022



“Being a partner of the International Federation is an added value for ASBI's growth, because it has allowed ASBI to widen its vision by empathising with others, sharing and learning from the best experiences. Cooperating with an international representative organization also means to improve the way the association works and communicates, to find joint solutions and to think overtly.

It is important for ASBI to be part of a strong International Federation that is committed to the promotion and protection of the rights of people with disability at EU and international institutions, because it is something that a national organisation cannot do alone. Receiving news, information and all opportunities that IF offers is paramount in order to understand how to advocate on a national level or what kind of actions are most needed in a specific period of time.”

***Maria Cristina Dieci, President of ASBI Italy***



“Each country must know the benefits that the International Federation for Spina Bifida and Hydrocephalus offers. Once you become IF member, your association will grow worldwide.

Thanks to that, APEBI was able to make a dream come true: to set the Latin American Spina Bifida and Hydrocephalus Network, after meetings with representatives of NGOs from different parts of the world, interacting with each other, with exchanges of opinions, APEBI together with our Federation, achieved it.

Today we can present RELAEBHI (Latin American Network for Spina Bifida and Hydrocephalus) thanks to the different supports of the members of IF. APEBI today coordinates the common interests of this Network made up of 15 countries.”



***Angel Torres, the President of APEBI  
and Elena Zúppoli, Former President of APEBI***

# LETTER FROM THE IF SECRETARY GENERAL

Dear (new) Member,



It is with great pleasure to present to you the renewed IF Membership Guide 2022. We trust this Membership Guide provides you with a valuable resource to navigate your benefits as Member and the opportunities available to support your work. IF membership and partnerships has grown over the years. It is truly inspiring to see what we can do together. Your active involvement is of unprecedented value.

In this guide, we provide you with opportunities for participation and collaboration. We encourage you to make the most of your membership. Did you know that as an IF Member, you can get access to all the information related to Spina Bifida and Hydrocephalus (SBH), resources, tools and professional development activities such as webinars, and training events; optimise your peer network and connection with different stakeholders not only within your region but all around the world. Moreover, as an IF Member, you can inform and shape IF's actions and policy on SBH.

We are here to support the great work you are doing in our SBH communities. We believe that having you together with other IF Members representing over 80 Associations Worldwide working on SBH is essential to promote and protect the full and equal human rights of people with SBH and ensure respect for their inherent dignity.

Looking forward to seeing each other soon.

Sincerely,

Dr Sylvia Roozen  
*Secretary General*

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# ABOUT IF

## WHO WE ARE

The International Federation for Spina Bifida and Hydrocephalus (IF) is the international organisation representing people with Spina Bifida and Hydrocephalus (SBH) and their families worldwide. The organisation founded in 1979, represents Member Associations in countries all over the world with unique and expert knowledge on SBH.

## MISSION & VISION

The **mission** of IF is to improve the quality of life of people with SBH and their families, and to reduce the prevalence of neural tube defects and hydrocephalus through primary prevention by improving maternal health literacy, raising awareness, political advocacy, research, community building, and human rights education.

The **vision** of IF is a society that guarantees the human rights of children and adults with SBH, and celebrates their contribution in all areas of life, while guaranteeing equitable access to maternal health literacy for all.

## VALUES

**Human Rights:** promotion and protection of human rights of people with SBH in accordance with the UN Convention on the Rights of Persons with Disabilities (UNCRPD) is our highest value.

**Participation & Inclusiveness:**

we take the views of children and adults with SBH and their families into account and rely on them in our work. We respect the regional, cultural and socio-economic specificities of our members around the world, and promote a tailored approach to working on SBH issues.

**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 & goals.

**Transparency & Accountability:**

IF works in a transparent & inclusive way, fully accountable to our members, donors and external stakeholders.



# OUR MEMBERS

IF's fast-growing membership now includes over 80 Spina Bifida and Hydrocephalus (SBH) associations in Africa, the Americas, Asia-Pacific and Europe.

Membership of IF is open to all national, regional and individual memberships and associated partners that share IF's vision and mission and actively involve people with SBH in their work. Organisations, institutions, companies and individuals with an interest in SBH and the aim to widen the extent of their activities are all welcome to apply for an IF membership.

IF respects and appreciates diverse community members and always strives for the solidarity and unity of all our works.



# OUR NETWORK



IF has forged alliances with key partners in the disability and human rights sector including private and public initiatives by civil society and knowledge institutes.

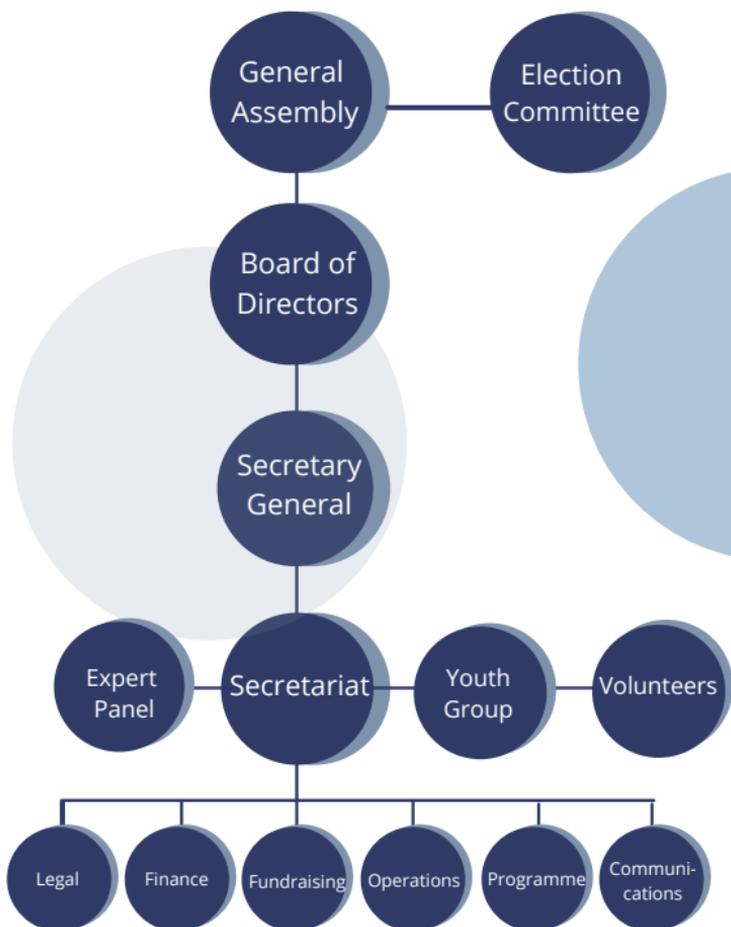
Through the Citizens, Equality, Rights and Values Programme, IF holds a privileged relationship with the European Commission. IF is a formal member of the European Commission Disability Platform.

IF is a full member of European Patients' Forum (EPF), European Organisation for Rare Diseases (EURORDIS) and is represented at the Board of the European Disability Forum (EDF), and the Board of the International Disability Alliance (IDA). To strengthen the work on primary prevention for SBH, IF allies with the Food Fortification Initiative (FFI) and other partners (e.g., WHO, UNICEF, Global Alliance for Improved Nutrition, World Food Programme).

IF holds Special Consultative Status at the Economic and Social Council of the United Nations. Furthermore, IF also fulfils several advisory roles in a variety of networks. For example, IF is the formal patient representative organisation in the ERN-ITHACA, serves as an expert in the IDA's youth with disabilities flagship, EUROlinkCAT, WHO RDI CGN4RD Panel and the UN Women's disability marker initiative. Also, IF participates in the WHO's Partnership on Maternal, Newborn and Child Health.



# OUR STRUCTURE



# MAIN REASONS TO BECOME IF MEMBER

1

## Be part of the strong and growing SBH community

- Join a network of over 80 Members Associations working on SBH worldwide.
- Be part of the international federation representing the global SBH community.
- Get inspired and benefit from the support of the whole SBH community.

2

## Build up your network

- Connect with different stakeholders not only within your region but all around the world including other organisations and individuals working with persons with SBH and their families, policy makers, healthcare providers, clinicians, and researchers.
- Have IF as the representatives in important forums (e.g., European Commission Disability Platform, IDA, RDI, EURORDIS, EDF and many others).

3

## Get access to shareable information and materials on SBH

- Gain insight into SHB topics through expert advice and scientific research.
- Benefit from information packages and practical educational materials such as toolkits, guidelines, etc.
- Get updated quickly and easily on latest news and upcoming events that really ma
- Receive regular e-Newsletters with information on the activities of IF, its' members and partners.
- Easily share this information and knowledge within your network.
- Improve your work with accessible and applicable educational materials.

4

### **Enhance your organisation's capacity**

- Benefit from a range of meetings, conferences, professional development activities, issue-based networks and up-to-date resources on topics that are crucial to the development and management of your associations such as policy and advocacy, project management skills, fundraising, communication and social media, etc.
- Expand the expertise of your association more quickly and easily with the guidance and opportunities offered by IF and other SBH networks.
- Be eligible to join different IF events and enjoy a reduced registration fee to the biennial International Conference on SBH\*

5

### **Fundraise better**

- Join a community of like-minded organisations and partners in fundraising initiatives.
- Increase your credibility, reputation and trust at the local and international levels as you are the member of an international federation.
- Gain visibility via our online and offline global presence.

6

### **Inform and shape actions and policy on SBH**

- Guide and receive guidance to contribute for the policy development at the local and national levels.
- Partner with IF and other networks in shaping policy at the global levels.
- Engage directly with the awareness raising campaigns organised by IF Shape your future.
- Participate or support in guiding IF international working groups (e.g., youth network, ageing group).

\* For individual members this will be determined on a case-by-case basis.

# HOW TO APPLY FOR OR RENEW YOUR MEMBERSHIP

To apply or renew your IF membership, please contact us at [info@ifglobal.org](mailto:info@ifglobal.org)

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## CONTACT DETAILS

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