



**Become a Member**



INTERNATIONAL FEDERATION  
FOR SPINA BIFIDA  
AND HYDROCEPHALUS

# MEMBERSHIP GUIDE 2026



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Being part of IF has given me a global family where lived experience is valued and transformed into action. Through IF and the Youth Group, I've connected with young advocates worldwide, strengthened my leadership, and ensured that the voices of people living with Spina Bifida and Hydrocephalus meaningfully shape advocacy, services, and policy.

**Dr. Nebiyat Tesfaye**

ReachAnother Foundation, ETHIOPIA



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Being a member of IF means joining a committed international network that fosters knowledge sharing, access to specialised resources, and collaboration among professionals, organisations, and people concerned. Membership enhances the visibility of local initiatives, supports the development of innovative projects, and provides opportunities to actively contribute to improving the quality of life of people living with Spina Bifida and Hydrocephalus - in our case also by hosting the 31st International Conference on Spina Bifida and Hydrocephalus in October 2026.

**Laurence Leser**

Spina Bifida and Hydrocephalus Association of Quebec, CANADA



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Participation in IFSBH offers SiBiAM members a platform to share ideas, connect with global peers, and learn from diverse perspectives and lived experiences. Members build meaningful international relationships while contributing to advocacy on ageing with spina bifida and women's rights. Through collective action, participation strengthens global advocacy and empowers lasting community impact.

**Su Xiao Vin**

Member of Spina Bifida Association Malaysia  
IMember of IF Working Group on Ageing with SBH



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Twenty years ago, when I became a mother to a child with Spina Bifida, my search for answers led me to the IF conference in Ireland, where many topics felt like true revelations. Soon after, the SPINA Foundation joined the IF. Today, we share knowledge, believing that meaningful exchange of experience and information is the Federation's core mission.

**Dominika Madaj-Solberg**

SPINA Foundation, POLAND



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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.

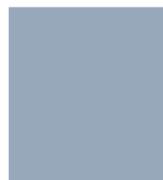
Thanks to that, APEBI was able to make a dream come true: to set the Latin American Spina Bifida and Hydrocephalus Network. After meetings, exchanges and interactions with representatives of NGOs from different parts of the world, APEBI together with the Federation, achieved it.

**Elena Záppoli & Angel Torres**

Asociación Para la Espina Bífida e Hidrocefalia, ARGENTINA



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# LETTER FROM THE IF SECRETARY GENERAL

Dear (new) Member,



It is with great pleasure to present to you the renewed IF Membership Guide 2026. We trust this Membership Guide provides you with a valuable resource to navigate your benefits as a Member and the opportunities available to support your important work.

IF membership and partnerships have grown over the years. It is truly inspiring to see what we can achieve together. Your active involvement and your country's representation within IF are essential in strengthening our collective voice and impact.

This guide outlines opportunities for participation, collaboration, and advocacy. As an IF Member, you have access to information on Spina Bifida and Hydrocephalus (SBH), professional development, peer networks, and global connections. Most importantly, you can help shape IF's actions and policies, ensuring your country's perspective is heard.

Together, with over 100 associations worldwide representing their countries, we can promote and protect the full human rights of people with SBH and ensure respect for their dignity.

We look forward to connecting with you and working together to make a difference.

Sincerely,

**Dr Sylvia Roozen**  
*IF 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. Founded in 1979, IF brings together 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 and 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 100 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.

[Find all members on IF website](#)



# 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 WORK



PREVENTION

RIGHT TO  
HEALTH

RAISING  
AWARENESS

INTERNATIONAL  
SOLIDARITY

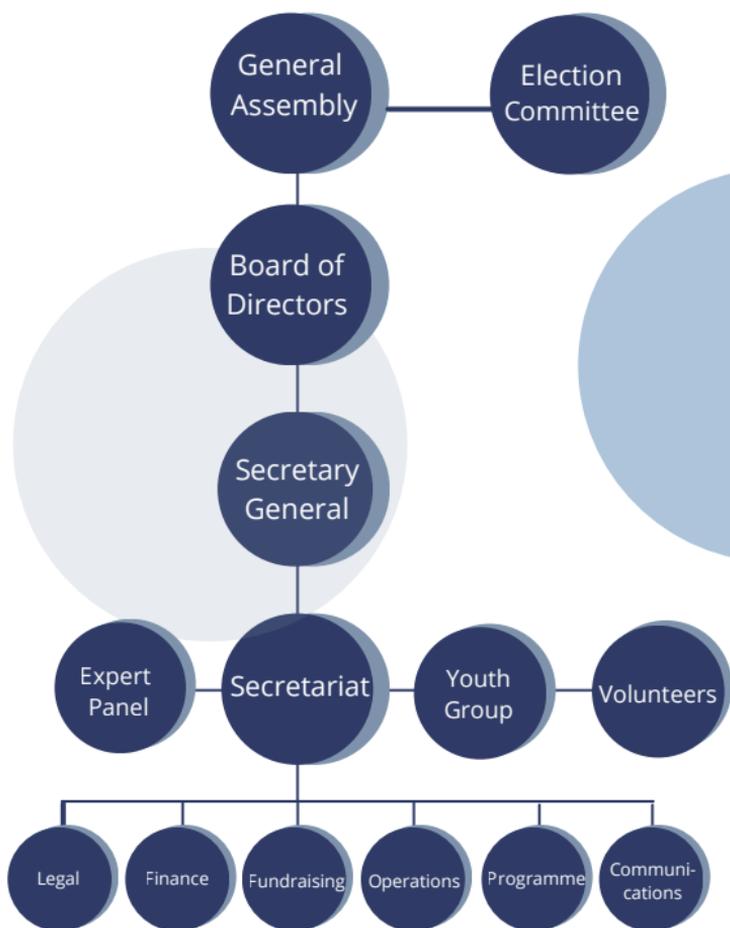
WORLD  
SBH DAY

HUMAN  
RIGHTS

COMMUNITY  
BUILDING

INTERNATIONAL  
CONFERENCES

# OUR STRUCTURE



# WHY TO BECOME AN IF MEMBER

1

## Be part of the strong and growing SBH community

- Join a network of over 100+ Member 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, WHO Disability Health Equity Network, 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 make an impact.
- 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.

### **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\*

### **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.

### **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.
- Participate or support in guiding IF international working groups (e.g., youth network, ageing group).

# 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).

The IF Team will be glad to assist you, answer any questions you may have, and provide all necessary information to guide you through the process.

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## CONTACT DETAILS

The International Federation for  
Spina Bifida and Hydrocephalus

 Cellebroersstraat 16,  
1000 Brussels (Belgium)

 +32 (0) 471 84 41 54

 [info@ifglobal.org](mailto:info@ifglobal.org)

 [www.ifglobal.org](http://www.ifglobal.org)

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