

# MEMBERSHIP GUIDE

2019

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# ABOUT IF

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 organisation of people with disabilities 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 holds **Special Consultative Status at the Economic and Social Council of the United Nations**.

Through the Fundamental Rights and Citizenship programme, IF holds a privileged relationship with the European Commission.

IF is represented at the Board of the European Disability Forum (EDF), the Board of EURORDIS and the Board of the International Disability Alliance (IDA). IF is part of the Executive Management Team of the Food Fortification Initiative (FFI).



## vision & mission

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Our vision of the future is a society that guarantees human rights of children and adults with SBH, and celebrates their contribution in all areas of life. A society that practices also primary prevention of neural tube defects and hydrocephalus.

The mission of IF is to improve the quality of life of people with spina bifida and hydrocephalus and their families, and to reduce the incidence of neural tube defects and Hydrocephalus by primary prevention, by raising awareness and through political advocacy, research, community building and human rights education.



# IF structure



# WHY JOIN?

## BENEFITS

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### Access knowledge on SBH

- Get access to expert advice & scientific research on SBH topics
- Get notifications on events related to SBH
- Receive regular e-Newsletters with information on the activities of IF, its' members and partners

### Join our events & trainings

- Become eligible to participate in trainings on a variety of topics: disability & human rights and prevention advocacy, project management skills, care to disabled persons, i.a.)
- Enjoy a reduced registration fee to the IF biennial International Conference\*

### Build up your network

- Be part of IF and interact with your peers - our members – by accessing IF's activities, list of members and updates
- Grow your own membership by joining the only international federation of national SBH organizations
- Consolidate your presence in forums IF is member of (EURORDIS, IDA, EDF & many others)



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

## **Fundraise better**

- Join a community of like-minded organizations and partner in fundraising initiatives
- Gain credibility and visibility via our online and offline global presence

## **Shape IF**

- Actively participate in IF's governing by becoming eligible to leadership positions

## **Shape your present**

- Be at the table, not in the menu: guide & receive guidance in shaping policy at the local and Global levels
- Engage directly with the awareness raising campaigns organized by IF

## **Shape your future**

- Join or support in guiding our youth network and/or ageing group



# MEMBERSHIP CATEGORIES AND FEES

The membership structure is divided into two main categories, moral entities and physical persons, and several subcategories.

- For moral entities, the categorisation, fee and voting is as follows:

ENTITIES	FEE	VOTE	SERVING ELIGIBILITY
National SBH associations	According to budget and <a href="#">country</a>	5	Yes
Other (non-national) SBH associations	According to budget and <a href="#">country</a>	1	Yes
Associate (universities, research centers, clinics, hospitals, i.a.)	According to budget and <a href="#">country</a>	0	Committees only
Corporate (pharmaceutical companies, components manufacturers, i.a.)	Sponsorship package to be decided	0	Committees only

The cap of votes per country is 10 votes.

SBH organisations are organisations where people with Spina Bifida and Hydrocephalus or relatives are in charge of the organisation.

The yearly membership fee would be fixed for the period of 4 years and would be determined as follows:

BUDGET IN €	FEE	ADAPTATION ACCORDING TO COUNTRY
Less than 5 000	80 €	According to the <a href="#">World Bank classification</a> of economies: - 25% low income countries - 15% lower-middle income countries - 5% upper-middle income countries Full fee for high income countries
Between 5 000 and 50 000	150 €	
Between 50 000 and 99 999	250 €	
Between 100 000 and 499 999	500 €	
More than 500 000	1000 €	

- For individuals that are not members of a moral entity (due to personal choice or the fact that there are no associations the individual can be member of)

INDIVIDUALS (without association)	FEE	VOTE	SERVING ELIGIBILITY
Full member (anyone interested in SBH)	Full fee (75€), adapted according to country of residence	0	Committees only
Young member (under 30) or person with Spina Bifida and Hydrocephalus	Reduced fee (30€) adapted to country of residence	0	Committees only
Professional interested in SBH	150€, adapted according to country of residence	0	Committees only

Note that individuals that are members of an organisation that is already a member of IF are NOT eligible to individual membership. Members that apply for individual membership whilst it is of IF's knowledge that there is a national association in their country will be incentivised to join that association to indirectly be members of IF; resistance to this would need to be justified by the individual member in question (e.g. serious disagreements with the national association in question).

# KEY LINKS

[Application form for entities](#)

[Application form for individuals](#)

[Annual and Financial reports](#)

[IF website](#)

If you have any questions or doubts about the IF membership structure, please do not hesitate to contact us at [info@ifglobal.org](mailto:info@ifglobal.org)





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