

SERVICE CLUBS IN ACTION FOR SPINA BIFIDA: PREVENTION AND CARE



A collaboration between Service Clubs &
Spina Bifida and Hydrocephalus Associations

"Each one of us can make a difference. Together we make change"

Service clubs and umbrella organisations such as the International Federation for Spina Bifida and Hydrocephalus (IF) have a lot in common due to their strong connections to their communities. IF advocates for policies to reduce the prevalence of Neural Tube Defects (NTDs) worldwide, and for actions to improve the quality of life of persons affected by Spina Bifida and Hydrocephalus (SBH) and their families. These priorities correspond with the areas of focus of many service clubs to improve maternal and child health. This text aims to explore our common vision of a fruitful future collaboration, building on the already existing strong partnerships between Service Clubs and people with SBH and their families that go back decades.

IF and SBH associations

The International Federation for Spina Bifida and Hydrocephalus (IF) represents people with Spina Bifida and Hydrocephalus (SBH) and their families, and is composed of grassroot member associations. IF mission is to improve the quality of life of people with SBH and their families and to reduce the prevalence of Neural Tube Defects (NTDs) and Hydrocephalus.

Thanks to medical advancements which enable children born with SBH to experience a normal lifespan, some countries are experiencing for the first time a population of people with SBH who are reaching old age (1).

However, where there is a lack of access to early interventions, SBH becomes a large contributor to mortality rates of children under five years of age. Other forms of NTDs are often, if not always, fatal, resulting in miscarriages, terminations, stillbirths or the death of the infant soon after birth. The regions that tend to have higher prevalence of NTDs also struggle to provide the necessary health care to ensure the survival and quality of life of people with SBH.

Decades of experience have demonstrated that the most impactful approach to reduce the prevalence of NTDs is to fortify staple foods with folic acid (2,3). Access to health care and reducing the prevalence of NTDs are crucial to improve maternal and infant health worldwide.

Service clubs

Service clubs are charitable organisations created and run by volunteers who meet regularly to discuss and perform charitable activities in their communities. The local clubs are the backbone of all service club organisations and it is there that individual members are affiliated and do the majority of the volunteering. The local clubs are then grouped into districts, which leads to national representations, and to the international umbrella organisation which encompasses these units. The volunteering takes place in accordance with common values and defined priorities at all levels of the organisation.


The most well known service clubs are organisations including Rotary International, Kiwanis International, and Lions Clubs International. These service clubs have been implementing impactful campaigns on maternal and child health with the promotion of preventative public health actions such as vaccinations. These campaigns are implemented in partnership with other organisations.

Examples of such campaigns include the joint Kiwanis International and UNICEF campaign promoting maternal and neonatal tetanus prevention, as well as the Rotary International Global Polio Eradication initiative through vaccination and immunisation programmes.


The common values and goals shared between service clubs and IF, coupled with the similarities in their organisational structures, make service clubs highly compatible partners for IF and its member associations to collaborate together.

A WINDOW OF OPPORTUNITY


IF collaborates with a variety of individuals and organisations in order to advance and enrich our advocacy. Cross-sector collaboration has been central to progress achieved by IF, and IF member associations, for example the Smarter Futures initiative (3).



Smarter Futures consisted of a multi-partner project which ran from 2007 to 2021. The project aimed to bring together actors from the public, private and civic sectors to support the implementation of national flour fortification programs and improve the nutritional quality of wheat and maize flour in Africa (3). Another recent collaborative success was the adoption by the **Seventy-sixth World Health Assembly of WHA76.19**, a resolution which also focused on reducing the prevalence of NTDs including SBH by addressing micronutrient deficiencies (4).



The Seventy-sixth World Health Assembly also saw the adoption of another landmark resolution for the SBH community, **WHA76.6 Strengthening Rehabilitation in Health Systems**. Among other things, the resolution stated that rehabilitation services contribute to the enjoyment of human rights, including the right outlined in Article 25 of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) which establishes the right to the enjoyment of the highest attainable standard of physical and mental health for persons with disabilities (5,8).



It is crucial that health care and support services for people with SBH are understood beyond the immediate surgical interventions and are approached with a holistic and lifelong perspective. These successes in advancing IF's mission to reduce the prevalence of SBH and improve the quality of life of people with SBH, were enabled by the partnerships with like-minded actors from all sectors - including but not limited to healthcare professionals, millers, civil society and representative organisations of persons with disabilities, international organisations such as the World Health Organization, as well as advocates in the fields of health promotion and nutrition.



COLLABORATIVE PROJECTS EXAMPLES

IF helps to facilitate and support partnerships between IF member associations and other organisations, including service clubs. Partnerships with Rotary Clubs and their local SBH associations and people with SBH and their families go back decades, as the focus areas of IF member associations align with the Rotary International work areas and efforts.

AN EXAMPLE ON LOCAL LEVEL | COLOMBIA – LATAM



In Colombia, a strong partnership has existed for more than 24 years between Rotary District 4271 and the local SBH association and IF Member, Fundación Monica Uribe Por Amor. Its director and current board member at IF, Sonia Uribe, is a strong figure among Colombian Rotarians. Sonia Uribe is a past Governor of District 4271, and belongs to the Rotary Club Nuevo Medellin. She was the first female Rotary district governor in Colombia. She is currently the DISC district international chair and president of ICC AI ternary to the community country of Colombia and the United states, and is the END POLIO coordinator for zone 25A for 2024.

The Fundación Monica Uribe Por Amor is very active in its community and has implemented many successful projects and awareness campaigns, some of which have received support from Rotary clubs.

The Fundación has had direct and indirect support from various Rotary clubs in the city. Its main objective is to seek comprehensive development in people with spina bifida, seeking their autonomy and social inclusion. Its place of impact is mainly Medellin, and it continues to be the only institution that exclusively attends to this condition in Colombia, where there are more than 430 families in 22 departments and 86 municipalities. The Fundación continues to constantly support each of the users to fight to fulfill their dreams and be someone useful to the family and community.

Rotarians in Colombia work together in a health committee to educate about the prevention of SBH and have utilised funding from the Rotary Global Grant to provide better quality of life for people with SBH and to educate on the importance of folic acid.



In Malaysia, in 2009 the Rotary Club of Damansara started an initiative on SBH in collaboration with the National Spina Bifida and Hydrocephalus Association (SiBIAM). Recognising the limitation of just one Rotary Club being involved led to the creation of the District Action Group for Spina Bifida and Hydrocephalus (DASH) in May 2019, with over a dozen clubs in District 3300 and 3310 currently participating. DASH's primary mission is to spearhead an awareness campaign on NTDs with a special emphasis on SBH. It is a collaboration between Rotary District 3300 and the National Spina Bifida Association of Malaysia (SIBIAM). With the support of The Rotary Foundation Global Grant, DASH initiated a project on raising awareness, and the development of an education program to be implemented in seven out of the 13 Malaysian states.

DASH is offering a platform for people with SBH and their loved ones to get information and to promote engagement in advocacy efforts in reaching out to the government and private institutions, schools and medical centers. Furthermore, DASH is aiming at enhancing the livelihood persons with SBH and their families by providing training to parents, volunteers and health care professionals focused on early intervention strategies, and the best approaches to care. A core ambition of DASH is to embark on a strategy to reduce the prevalence of SBH through national awareness campaigns focused on the fortification of staple foods with folic acid.

The global grant project workshops were successfully implemented in the seven states between July 2021 and June 2023 and involved the participation of various healthcare professionals, as well as persons with SBH and their families. It included a session moderated by persons with SBH. Bringing together the expertise of the two groups demonstrated the value of co-production with persons with lived experiences with SBH in initiatives for the education of health care professionals. In total, almost 1200 persons were involved which this initiative including almost 500 health care professionals, 300 SB individuals and their carers and over 300 volunteers including Rotarians.

This Global Grant partnership was possible due to a multi-district involvement with Rotary clubs from India, Indonesia, Singapore as well as Malaysia. It is in line with the objectives of DASH to connect with Rotary districts globally to bring attention to SBH within the Rotary work areas on 'maternal and child health' and 'disease prevention and treatment'.

The 30th International Conference on Spina Bifida and Hydrocephalus in Kuala Lumpur

Another positive outcome is the 30th International Conference 'Bridging the healthcare and prevention gaps – A multidisciplinary team approach with the community at heart' organised in October 2024 in Malaysia, by SIBIAM in collaboration with IF and with Rotary's support. This conference resulted in a historic [Kuala Lumpur Declaration](#) (6) that is open for co-signatures.



IF AND SERVICES CLUBS:

A COMMON VISION FOR COLLABORATION

IF and service club partnerships bring together the SBH community and the perspectives of persons with lived experiences of SBH to charitable activities undertaken by services clubs on the local, regional and international level.

The common values and goals shared between service clubs and IF, coupled with the similarities in their organisational structures, make service clubs highly compatible partners for IF and its member associations to collaborate together.



By connecting the SBH community to the charitable activities of service clubs, IF and service clubs can rely on a shared pool of expertise and resources to create projects that are greater than the sum of their parts.

All IF core activities also seek to advance the rights of people with SBH and their families. Consequently, IF has forged strong relations with various international organisations active on disability rights, healthcare and prevention. IF is therefore, ideally positioned to facilitate dialogues between Rotarians, IF member associations, representative organisations for persons with disabilities, international organisations and their agencies, healthcare professionals, knowledge institutes and other relevant partners.

With IF's past successful collaborations, the Federation is highly experienced in creating and implementing collaborative projects in the regional and global level. The Federation is ready to embark on a similar equal partnership with service clubs to advance the mutual vision of improving maternal and child health by reducing the prevalence of NTDs including SBH, and to raise the quality of life for people with SBH and their families. We will do that by creating strategies informed by decades of experience working with global connections and local communities alike through IF's member associations and an additional vast network of world-leading experts in the field of health and nutrition.

IF will play a key role in future collaborations with service clubs, promoting awareness of SBH and on how its prevalence can be reduced without inadvertently stigmatising the SBH community, in line with the UN CRPD.

By partnering with representative organisations of persons with disabilities such as IF, service clubs ensure that their activities are created in line with a fundamental value of the rights of persons with disabilities, where the key is "Nothing about us without us".

Furthermore, to strengthen coordination between service clubs, IF welcomes learning more about the work currently being done in support of our global SBH community.

Whether you are an IF member association, a person with SBH or a family member, a member of a service club or just interested in learning more about collaborations between SBH associations and service clubs, please do not hesitate to contact the IF secretariat at info@ifglobal.org.

MORE INFO

What is Spina Bifida and Hydrocephalus?

Spina Bifida is a type of NTD which is a group of birth defects that form when the neural tube fails to close during pregnancy, affecting the brain and spinal cord. These defects form very early in pregnancy, often before the pregnancy has been detected.

Most children with Spina Bifida also develop Hydrocephalus, a condition where the cerebrospinal fluid accumulates in the brain. SBH can affect mobility, bowel and bladder control, and cognitive functions. The survivability relies on early access to specialised surgical interventions, long-term access to multidisciplinary care, life-long support, and through the full realisation of human rights and societal inclusion (7).

What is food fortification?

Food fortification is a process where micronutrients are added to commonly consumed foods to improve nutritional quality. Fortifying staple foods with folic acid is mandatory in many countries.

What is the UN CRPD?

The United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) is an international human rights treaty of the United Nations intended to protect the rights and dignity of persons with disabilities. Parties to the convention are required to promote, protect, and ensure the full enjoyment of human rights by persons with disabilities and ensure that persons with disabilities enjoy full equality under the law (8).



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References

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5. World Health Organization (2023). [Resolution WHA76.6 Strengthening rehabilitation in health systems.](#)
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