

FOLATE TASK TEAM

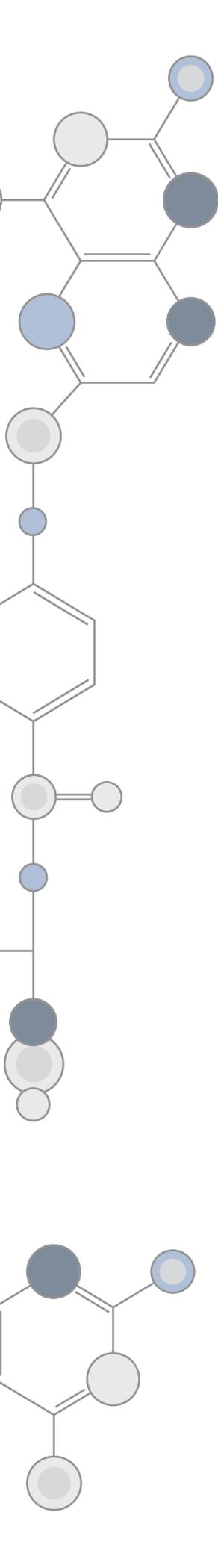
PREVENTING NEURAL TUBE DEFECTS IN LOW AND MIDDLE INCOME COUNTRIES AND THE IMPORTANCE OF REPRESENTATIVE ORGANIZATIONS

*KNOWLEDGE
BRIEF*



Nourish Life





This brief was developed in partnership with the International Federation for Spina Bifida and Hydrocephalus. The Folate Task Team would like to express its gratitude to Lieven Bauwens, Martine Austin, and Renée Jopp for their contributions.

ABOUT THE FOLATE TASK TEAM

The Folate Task Team comprises a group of global experts and partners under the leadership of Nutrition International (NI) through NTEAM (Nutrition Technical Assistance Mechanism), all joined together to identify priority actions to reduce folate-sensitive neural tube defects, build laboratory capacity for the assessment of folate status, support research in this critical area and to facilitate access to folate-related knowledge products.

Through NTEAM, NI shares its expertise globally to support the scale-up of nutrition for the most vulnerable. We believe that knowledge, rigorously obtained and generously shared, is key to effective progress for nutrition. NTEAM convenes global experts to tackle key nutrition issues and encourage broad use of knowledge by translating technical information and research into accessible guidance, tools and resources. We also work with countries and agencies, sharing expertise through timely and coordinated technical assistance.

ABOUT THE INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

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 organization (DPO) with global coverage, democratic structure and transparent and accountable processes.

The majority of IF member organizations 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 organizations. 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.

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**The Role of Representative
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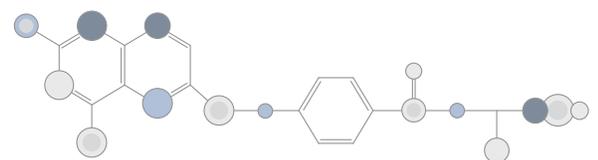
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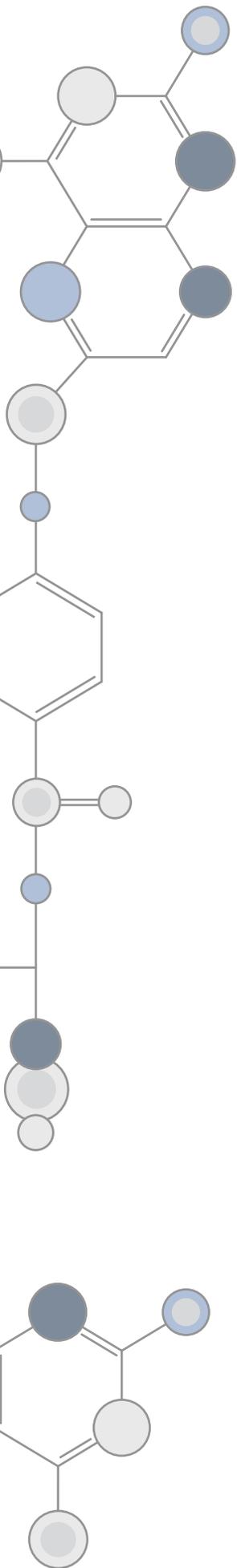
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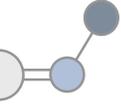


WHAT WE KNOW

Neural Tube Defects (NTDs) are a group of birth defects – including anencephaly and spina bifida – that affect brain and spine development in a fetus during the first four weeks of pregnancy, usually before a woman knows she is pregnant. NTDs are complex, multifactorial conditions, but we know that low maternal folate levels during the critical preconception period and in the very early stages of pregnancy present the single greatest risk. In 1991, a groundbreaking study by the Medical Research Council proved that timely supplementation with folic acid at the correct dose could prevent up to 72 percent of cases.¹

Anencephaly is the most severe form of NTD, resulting in early death (before, or shortly after birth), while spina bifida – with timely and adequate treatment – is compatible with life. It can, however, result in varying degrees of lifelong disability. Damage to the spinal cord may cause paralysis and loss of sensation, resulting in incontinence and mobility issues. Both can be addressed through access to assistive products², such as urinary catheters for continence management, cones for bowel management and orthoses, crutches or wheelchairs to move around. However, these may not always be available or affordable to families living in low- and middle-income countries (LMIC).

Over 85 percent of babies born with spina bifida will also develop hydrocephalus, a condition involving an excessive build-up of fluid in the ventricles of the brain, compressing tissue and placing increased pressure on the brain. When left untreated, brain tissue will be damaged and death may occur, but this will not be immediate. In newborns, the skull bones will not have fused yet and the accumulated fluid will stretch and expand the skull. As a result, the head of a baby with hydrocephalus will become



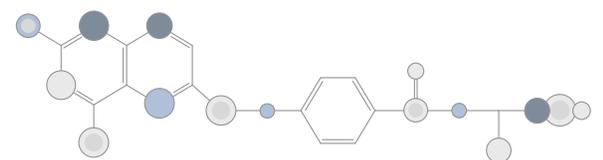
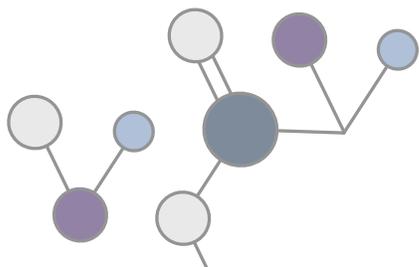
much larger than other babies of the same age. The continued pressure on their brain tissue will affect their vision, their cognition, their ability to walk, and in severe cases babies and young children will not be able to lift their head and will be completely dependent on their parents' care. Care falls directly on the family and creates a lot of financial hardship and stress.

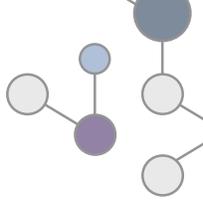
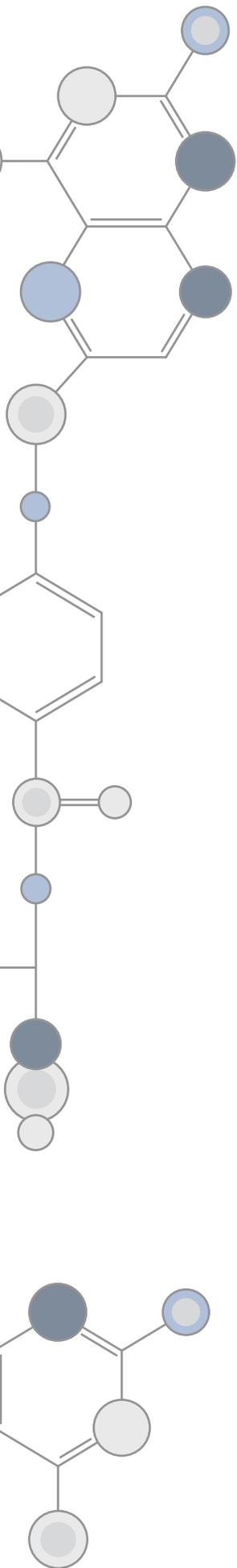
In some countries both children with spina bifida and their parents face social stigma, not only from the wider community, but also from within their own families. In some cultures, women may be left to raise their child completely unsupported and are kept isolated in their home, while their husbands may be forced to remarry.

In LMICs, access to treatment for spina bifida and hydrocephalus can be difficult, especially for people living in rural areas and for those living in poverty, who are at greater risk of malnutrition and the associated adverse pregnancy outcomes, such as NTDs.

Apart from geographical and/or social barriers, another challenge is that the proportion of neurosurgeons available and properly trained to treat neurosurgical disease is critically low in LMICs.³ Yet NTDs have the largest potential for successful intervention, should the surgical programs be scaled up to 100 percent coverage, with 76 percent of burden preventable by surgery.⁴

Comprehensive reviews of existing studies and surveillance systems consistently observe that several LMICs lack systems for identifying birth defects or mandatory reporting by healthcare providers.⁵





THE IMPORTANCE OF PREVENTION IN LMIC

The health infrastructure of many LMICs is often not very advanced, and may be all but non-existent in some regions, especially in more rural areas. Many LMICs still largely rely on international aid for the maintenance of healthcare systems.

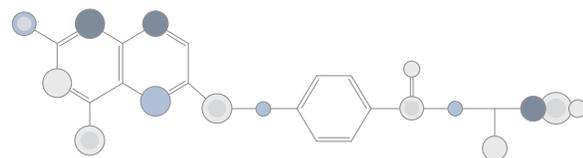
Whilst access to prenatal screening and elective terminations dramatically influences the live birth incidence of NTDs in developed countries, the majority of parents-to-be in LMICs will not have access to standard prenatal care, such as a 20-week ultrasound for fetal anatomy. There are also disparities in access to treatment and care from one region to another, particularly between those living in urban and rural areas, and because in many countries, elective termination of pregnancy is not a legal option. Therefore, the first time that the majority of women will learn that their baby has an NTD is usually at birth. Cultural beliefs and superstition may cause women to be scared and think that their baby is cursed if it is born with a birth defect. Some may choose to hide or abandon their child out of fear of being ostracized. Others may recognize that medical treatment is needed, but may not know how or where to gain access. A father may leave his wife and child when the baby has a disability, creating financial hardship and difficult living circumstances, which makes it even harder to find support. The best possible scenario is that newborns with spina bifida and/or hydrocephalus are registered at birth and have access to appropriate treatment and care as soon as possible, with parents receiving appropriate information and all necessary services to look after their child. Unfortunately, this does not happen for many. A shortage of neurosurgeons³ may be exacerbated by lack of expertise in managing this condition. Likewise, general knowledge about NTDs may be lacking among parents and the community at large, and outdated views (or innate cultural beliefs) may persist in both the medical community and the general population, so children born with disabilities—and their families—endure stigma and discrimination.

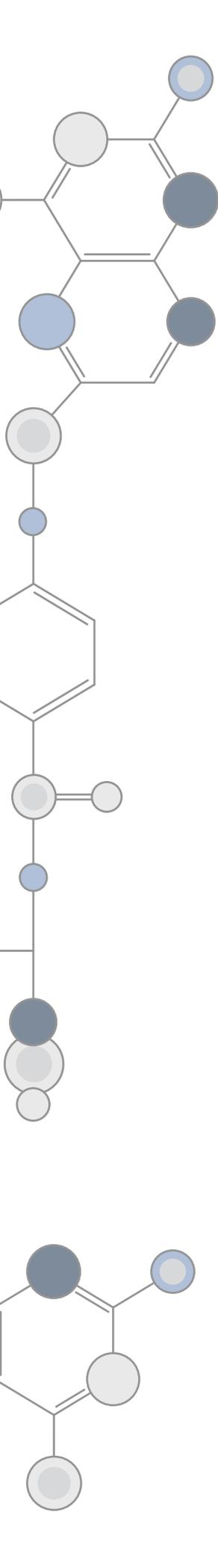


Where treatment is available, the costs of surgery, medical devices, travel to and from the hospital, and necessary assistive products can create an additional barrier for children born with spina bifida and hydrocephalus in LMICs. Even where barriers are overcome to access lifesaving treatment (such as surgery to insert a shunt), the cost of, and access to, vital follow-up treatment can prove prohibitive, leading to potentially life-threatening infections or device failure. In contrast, food fortification is an effective primary prevention intervention.

Mandatory large-scale food fortification of widely consumed staple foods in LMICs will help decrease burden on families and reduce demand on financially strained health systems, especially those that provide free healthcare. For example, in Ethiopia medical treatment is free to children under the age of five, but the live birth rate of babies affected by NTDs is up to 13.8 per 1,000 births, creating a demand which the health care system cannot meet.⁶ An effective large-scale fortification program could greatly reduce the burden, and may have a further benefit of increasing investment into services and care for those that are still affected by these conditions.

Maximizing the potential for prevention of NTDs in LMICs will help ensure that less children die and more children have the chance to survive and thrive, without stigma and increased risk of poverty as a result of reduced earnings and the financial burden of treatment.





NTD PREVALENCE

Multiple studies have attempted to measure the prevalence of neural tube defects in LMICs, each concluding that there is a paucity of data. In 2014, Lo et al. concluded that “Limited available data on NTD in LMIC indicates the need for additional research that would improve the estimated burden of NTD and recommend suitable aid policies through maternal education on folic acid supplementation or food fortification.”⁷ Two years later, Zaganjor et al. found that “Despite methodological variations and coverage gaps in data collection, high NTD prevalence estimates throughout the literature indicate that NTDs remain an important preventable public health problem.”⁸ More recently, Blencowe et al. stated “Our systematic review showed a paucity of high-quality data in the regions of the world with the highest burden. Despite knowledge about prevention, NTDs remain highly prevalent worldwide. Lack of surveillance and incomplete ascertainment of affected pregnancies make NTDs invisible to policy makers.”⁹ These authors also point out that “even the most comprehensive systems fail to capture spontaneous miscarriages and early fetal losses, where detailed investigation is rarely undertaken.”⁹

Therefore, looking only at measurable birth outcomes (live births, stillbirths, and elective terminations of pregnancy for NTDs) does not provide insight into the true prevalence of NTDs in a country. Also, not all countries record the cause of stillbirths or they will classify stillbirths differently.¹⁰ Blencowe et al. point out that “Prevalence is largely under-ascertained and is highly variable, particularly in LMIC without a capacity to use multiple data sources and limited tracking of elective termination of pregnancy for fetal impairment (eTOPFA) and stillbirths due to legislative or cultural barriers.”



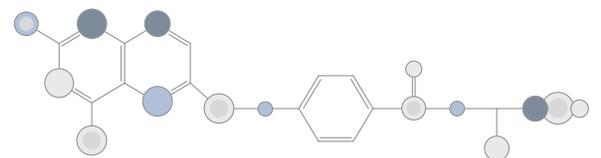
Birth Defect Surveillance

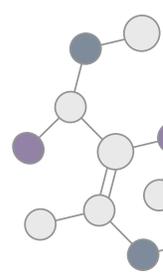
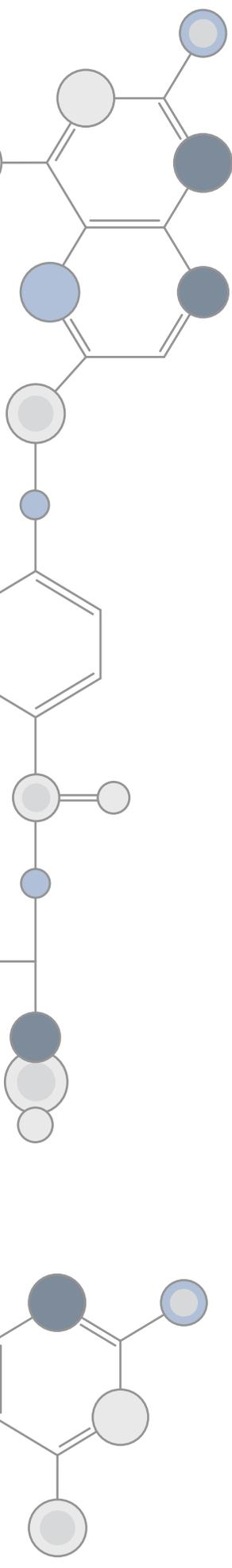
As stated by the World Health Organization (WHO),

“Most LMICs have no birth defects surveillance. When data are available, they are mostly obtained from individual, one-time studies rather than ongoing surveillance. For countries with established systems, surveillance is usually local or regional only and is typically facility based; sampling therefore is not population based or nationally representative. Surveillance facilities are often referral centers, making it difficult to obtain unbiased data or calculate rates.

LMICs face numerous challenges in detecting and reporting birth defects, including limited resources, inadequate infrastructure, and lack of expertise. Capacity for accurate diagnosis, coding, data management, and analysis is generally lacking. Above all, political will often falls short in LMICs where numerous other serious health problems compete for limited resources.”¹¹

The WHO has developed tools for birth defect surveillance, including a database (with apps for smartphone accessibility),¹² a facilitator’s guide,¹³ a manual for program managers¹⁴ and an atlas of selected congenital anomalies.¹⁵





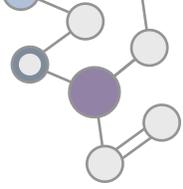
BARRIERS

Barriers to prevention in LMIC

While barriers to NTD prevention exist in all countries (such as the challenge of reaching women before they conceive and the general lack of awareness about the role of folic acid in preventing NTDs), a complex combination of cultural, social and economic factors pose significantly greater challenges in LMICs.

Firstly, good preconception health requires good nutrition. An **insufficiency of folate** in a mother's body increases the risk of the fetus developing NTDs. Malnutrition affects almost half of the world's population, with those living in LMICs being at greatest risk of nutritional deficiency. **Economic and cultural reasons** often limit access to nutritionally complete foods. These may be harder to come by or unaffordable to certain population groups; culinary practices in some countries lead to some foods being cooked for long periods, further depleting their nutritional content; in many cultures women will eat last, ensuring that their children's and partners' nutritional needs are met first, placing them at higher risk of inadequate intake. Fasting for prolonged periods, which is practiced in some cultures even during pregnancy, is another risk factor for inadequate intake. Subsequently there is a high incidence of folate and iron deficiency related anaemia within women of reproductive age (WRA).¹⁶

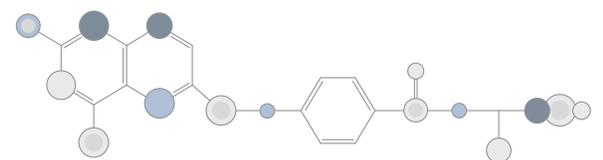
Lower levels of **education** are directly linked to health and nutritional status,¹⁷ with more educated women more likely to have healthy children and less likely to die in childbirth. Health literacy in many LMICs is often poor, and there is little public awareness of the need for supplements, fortified food products and folate rich foods, as well as a lack of understanding and awareness about the importance of preconception health and nutrition. When these nutritional risk factors are present, pregnant women are at greater risk of having fetuses that develop NTDs. There are also widespread **misconceptions about folic acid** and its function, with men in some cultures believing folic acid to be a form of

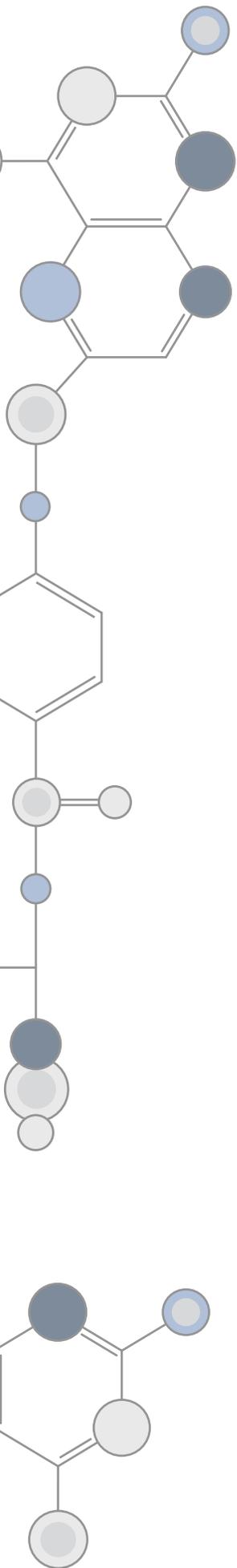


contraception, and subsequently not permitting their wives to take these vital supplements.

Lack of, or lack of access to, **qualified health professionals** means that many women in LMICs do not have access to preconception care and family planning advice. In some LMICs there is widespread faith in traditional healers and birth attendants, with an associated skepticism of health professionals and “modern medicine”. Many new mothers follow the example set by their own mothers and communities. Most women only access health services (where available) on presentation of pregnancy recognized by the absence of their regular menstrual period, meaning that they will seek medical care at 12 or more weeks gestation. This is usually when women may receive advice to take folic acid supplements if available. By this time, however, it is much too late to reduce the risk of NTDs. Even where supplements are available, the cost may be prohibitive. Inadequate birth spacing further increases the risk of nutritional depletion. Furthermore, the absence of prenatal diagnosis means that affected pregnancies are often only diagnosed at birth, leaving parents both completely unprepared, and without the options afforded to those living in wealthier countries.

As has been shown by numerous studies, large-scale mandatory food fortification of adequate food staples is an extremely cost-effective way to reach large segments of the population to improve their micronutrient status. Some challenges that emerge where food fortification has not yet been mandated by the government include a **lack of commitment** from business/commerce towards dealing with challenges related to fortification. Even where mandates exist, there are widespread issues with implementation, monitoring and compliance, with increasing business competition leading to corruption. As a result, the folate levels within fortified foods are often non-existent, inaccurate or inconsistent.





Finally, lack of/or **incomplete monitoring and surveillance of birth defects** means that the true burden of NTDs in many countries is either unknown or, at best, extrapolated from data emanating from small scale hospital based study data. Lack of a complete assessment of the burden of NTDs may be a deterrent to governments to establish appropriate practices to reduce the risk of these conditions.

Malaria endemic regions

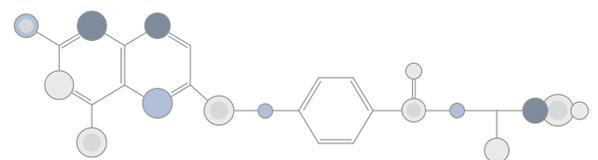
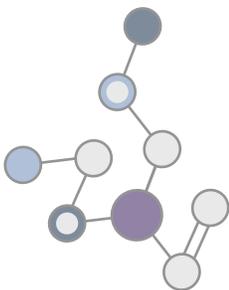
On a public health level, there are often many **competing health priorities** in LMICs with prevention and treatment of communicable and infectious disease (i.e. malaria), which are often at the forefront of public health policy.

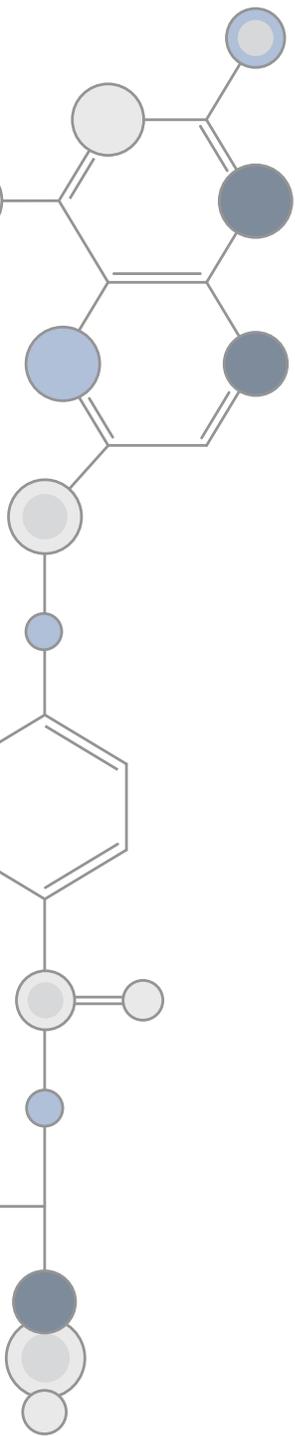
Intermittent preventive treatment for malaria is recommended by the WHO for all pregnant women in malaria endemic areas because of the serious risks associated with malaria in pregnancy.¹⁸ However, the use of antimalarial medication can have an impact on folate levels, because antimalarials are also antifolates.

The malaria parasite needs folic acid to thrive, but it does not use metabolized folic acid in the blood, it only targets un-metabolized folic acid. Whilst small doses of folic acid (400 mcg) are fully absorbed by the body, higher doses will result in “free folic acid” in the blood, which will benefit the malaria parasite, decreasing the effectiveness of antimalarial treatments.¹⁹ Higher daily doses of 5 mg are recommended by the WHO for women who are at risk of having a pregnancy affected by an NTD.²⁰ This includes women who have already experienced an NTD-affected pregnancy, couples who have spina bifida or who have a family history of NTDs, women with diabetes, women taking certain anti-seizure medications for epilepsy, women with coeliac disease or other conditions that affect intestinal absorption, and women that are very overweight/

obese (BMI >30 kg/m²). There is no scientific evidence to suggest that the regular 400 mcg dose of folic acid has any impact on the effectiveness of malaria medications.

Whilst high doses of folic acid are not needed during low-risk pregnancies, in some countries (such as those in Africa) the higher 5 mg dose folic acid supplement is commonly the only dose option available to women, despite lower doses also being included on the WHO essential medicines list.²¹ It is vital that availability of the recommended (400 mcg) dose of folic acid supplements is improved in malaria endemic regions. The 5 mg dose of folic acid should be reserved **only** for specific clinical cases, such as risk of recurrence, or where a woman is at higher risk due to any of the other known factors (i.e. epilepsy medications, diabetes mellitus, etc.). Failure to do so may inadvertently result in a doubly negative impact: increasing a pregnant woman's risk of malaria without reducing the risk of NTDs.





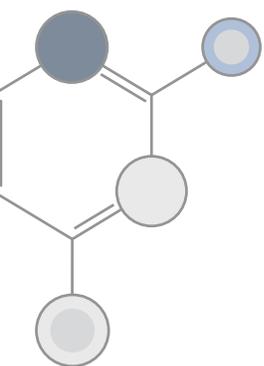
THE ROLE OF REPRESENTATIVE ORGANIZATIONS

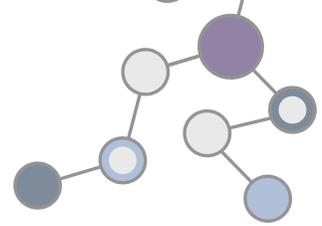
Representative organizations (RO) of those affected by NTDs are typically locally embedded, **want to be** involved, and want support so they can lead on related issues at the country level. Their involvement is supported by the UN Convention on the Rights of Persons with Disabilities (UN CRPD) (4.3, 33.3), which states “Nothing about us without us.”²² Whilst ROs can greatly differ in terms of experience and capacity to advocate and voice the concerns of people living with spina bifida and/or hydrocephalus, they are united around a common vision, which includes a commitment to both improve the quality of life for people with spina bifida and hydrocephalus and their families. This includes the vision to reduce the incidence of NTDs and hydrocephalus through primary preventions such as food fortification with folic acid and supplementation, raising awareness, political advocacy, research, community building, and human rights education.

Expert Knowledge and Unique Voice

Without awareness of the conditions themselves, prevention measures are less likely to be taken as seriously as they should. ROs are in a unique position to raise awareness of NTDs on the national and community levels drawing attention to the reality of what it means to live with spina bifida and/or hydrocephalus.

With their lived experience, children and adults with spina bifida and hydrocephalus and their family members contribute to advocacy efforts and play a role in monitoring prevention measures that have been implemented. In meetings with government representatives and industry, they are best placed to explain the consequences of not taking prevention measures to reduce the incidence of NTDs. There are some very positive working examples of highly effective collaborative approaches between patient groups, their members, industry, consumer associations and ministries of health.

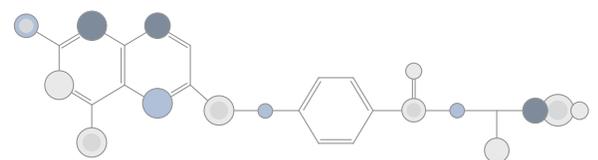


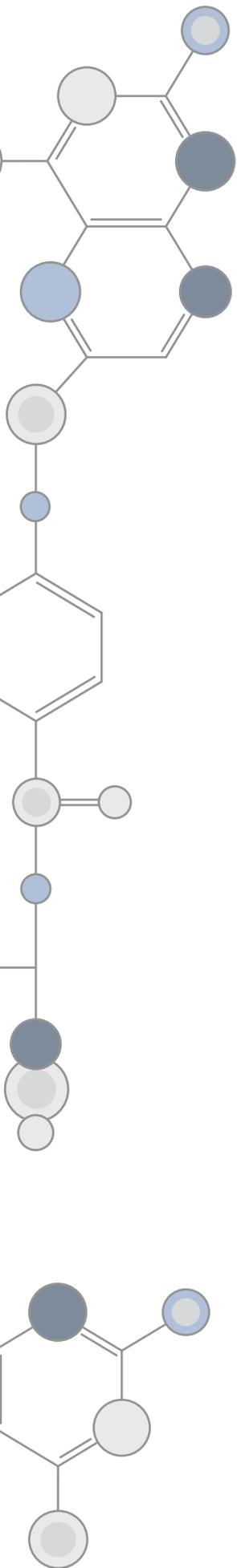


ROs are uniquely motivated to help ensure and drive accountability as they are already focused on addressing issues facing women, children and people with disabilities. They protect and promote of the rights and benefits of target groups (through care and support programs), and play a pivotal role in provision of social welfare services (formal or informal). They have a **true awareness** of the impact of “non-compliance” of prevention measures. The Global Fortification Technical Advisory Group (GF-TAG) is a working group committed to maximizing sustainable global food fortification, building engagement at regional, national and global levels. GF-TAG identified the International Federation for Spina Bifida and Hydrocephalus (IF) and its member organizations as key stakeholders in improving fortification program outcomes and increasing compliance.

The impact of ROs has also been mirrored in LMICs with the PULL strategy, which was implemented in 2018. This approach involved ROs (IF member organizations in Malawi and Uganda), consumer associations, and relevant civil society organizations advocating the governments for improved enforcement and compliance (by industries) of fortification standards, while creating awareness among the general population of the importance of fortified foods. The IF member organizations were actively involved in taking and analyzing product samples, contacting manufacturers to advise of any irregularities (offering them the opportunity to comply) and identifying compliant manufacturers as examples of good practice.

ROs have a unique understanding of the cultural environment, including the cultural barriers related to diet and religious beliefs that often prevent compliance. Even once national policies are in place many women and their partners distrust government officials and health professionals,





following advice from within their communities. ROs help to bridge this communication gap between authorities and the target groups. Often policy makers do not appreciate the severity of the NTD issue, so raising awareness from within the community is essential to develop an understanding of the urgent need for both primary prevention and care.

ROs have a further important role to play in advocating for the implementation of birth registries which can capture all NTD data (as recommended by the WHO), but this engagement needs to be universally encouraged. To fully understand the true burden of NTDs, birth registries must capture relevant data to inform policy and strategy for prevention and care.

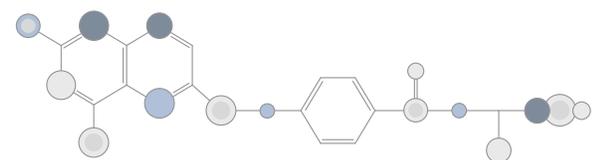
Protecting the dignity of people born with disabilities

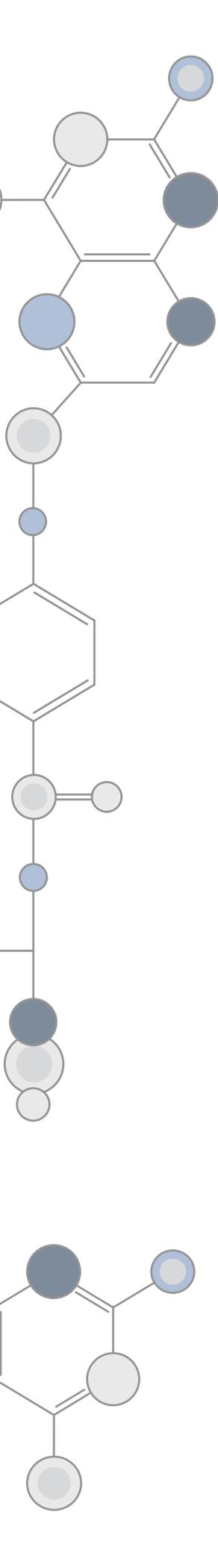
When introducing measures to prevent NTDs, it is essential that associations and groups of persons with spina bifida and hydrocephalus—and their family members—are consulted and involved to ensure that primary prevention campaigns do not carry hidden, discriminatory messages to safeguard the dignity of people born with disabilities.

Preventing NTDs should not cast a judgement on people living with these conditions, nor should it indicate that they are a burden to society. Families who have a child with an NTD should not be made to feel guilty. Children with disabilities have the right to be raised by their parents and should not be separated from them against their will. Parents and society should understand that spina bifida and hydrocephalus are not curses, and that these conditions can be treated.

KEY MESSAGES

- It is essential to improve birth registration, data collection and surveillance to fully understand the extent of NTD prevalence in LMICs and monitor the effectiveness of prevention strategies.
- Some neural tube defects – such as spina bifida – can be treated, yet the necessary neurosurgical expertise and the required number of neurosurgeons are often not available in LMICs, and this causes unnecessary suffering.
- People in rural areas, people of low economic status, and people with low levels of education are at greater risk of having a pregnancy affected with an NTD, yet also face the greatest barriers in accessing care and support, and healthy diets. This is particularly evident in LMICs.
- Well-implemented, large scale mandatory fortification of food with folic acid can significantly reduce the prevalence of NTDs; it requires no change in diet, is cost-effective, provides a high return on investment, and reduces inequalities.
- Greater availability of the 400 mcg dose of folic acid is needed, and availability must be extended to all WRA, not only those presenting with a pregnancy.
- Improved health education and awareness is essential for all women of childbearing age, to help dispel any misconceptions about folic acid.
- Preventing NTDs in LMICs remains key in efforts to reduce neonatal and under-five mortality.
- Associations and groups of persons with spina bifida and hydrocephalus – and their family members – need to be consulted and actively involved in prevention strategies, campaigns and monitoring, to provide “inside” knowledge and insight, a unique drive to succeed, and to safeguard the dignity of people with a disability.
- Primary prevention of NTDs is a highly cost-effective public health intervention.²³

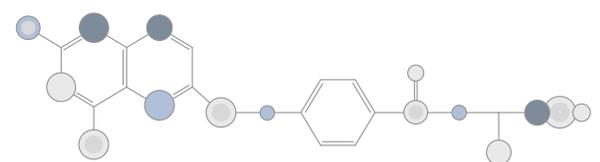




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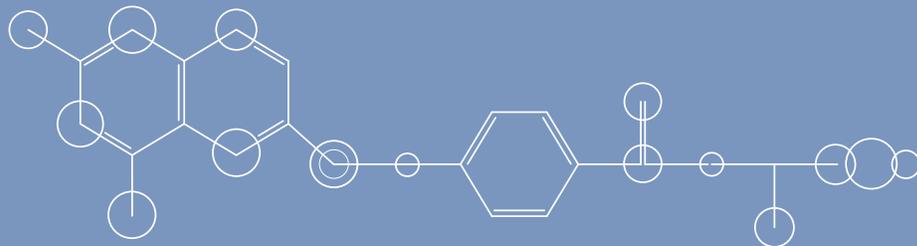
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