



## IF Statement A call for a global action to reduce the prevalence of Neural Tube Defects worldwide

### **Introduction**

The International Federation for Spina Bifida and Hydrocephalus (IF) is calling for urgent action demanding universal mandatory food fortification with vitamin B9 (folic acid) to reduce the risk of Spina Bifida, Anencephaly, or Encephalocele, also called Neural Tube Defects (NTDs). Decades of evidence have demonstrated that mandatory fortification of staple foods with Vitamin B9 is the most effective and cost-efficient method to reduce the prevalence of NTDs. While promotion of voluntary dietary changes has been shown to be ineffective, mandatory fortification of food staples with vitamin B9 has repeatedly been proven to be highly effective in reducing NTDs. Countries that have introduced mandatory fortification of vitamin B9 in staple foods have seen a drastic reduction in the rates of Spina Bifida and other NTDs <sup>(1)</sup>.

Vitamin B9 is a micronutrient. Micronutrients are vitamins and minerals available in different kinds of foods. Maternal intake of vitamin B9 before and during pregnancy reduces the risks of NTDs because vitamin B9 <sup>(2)</sup> is essential for a healthy periconceptional period, being the 14 weeks before and 10 weeks after conception.

This statement outlines (1) what NTDs are, (2) how NTDs are affected by the social determinants of health, (3) what food fortification is and how it reduces the prevalence of NTDs, (4) the economic benefits of food fortification, (5) the stakeholders that need to be involved to make mandatory fortification of staple foods with folic acid a global reality, (6) the primary prevention of NTDs in the context of disability rights, (7) the need for an effective rights-based approach for the primary prevention of Spina Bifida and other NTDs, (8) IF's recommendations on achieving a global reduction in the prevalence of NTDs through food fortification.

### **Neural Tube Defects**

Neural Tube Defects (NTDs) include Anencephaly, Iniencephaly, Encephalocele, Spina Bifida and their combinations, and secondary consequences. NTDs are birth defects affecting the brain and the spinal cord early in the pregnancy, often before the pregnancy is detected. They occur when the neural tube fails to close resulting in malformations of varying severity <sup>(3)</sup>. It is estimated that a minimum of 20 per 10,000 births are affected by NTDs worldwide. However, the prevalence of NTD-affected pregnancies is likely to be much higher since these numbers are based on live births and do not take into account miscarriages or termination of the pregnancy <sup>(1)</sup>.

Spina Bifida is a result of the neural tube not closing correctly, resulting in damage to the spinal cord and nerves. The effects of this damage depend on the size and location of the opening in

the spine. Spina Bifida is the most common NTD and most children with Spina Bifida also develop Hydrocephalus, a condition in which cerebrospinal fluid accumulates in the brain. Hydrocephalus requires urgent surgical intervention to prevent blindness, brain damage, and death. Spina Bifida and Hydrocephalus (SBH) are complex health conditions that lead, in many cases, to disabilities affecting mobility, bowel and bladder control, and cognitive functions. Early access to diagnosis and medical care, including access to specialised surgical interventions, is essential for the survival and long-term wellbeing of persons with SBH. They need access to life-long person-centred multidisciplinary care and support to realise their human rights, societal inclusion and potential <sup>(4)</sup>.

Other forms of NTDs have even more serious outcomes. Anencephaly is a fatal condition where the brain does not develop either partially or, in some cases, at all. This results in miscarriages, termination, stillbirths or the death of the infant soon after birth. This is also the case for pregnancies affected by iniencephaly, an NTD that results in malformations of the head, neck, and spine. When a pregnancy affected by iniencephaly results in a live birth, the infant rarely lives longer than a few hours. Finally, encephalocele is a sack forming where the bones of the skull fail to develop, leading to brain damage and sometimes death. These birth defects can be significantly reduced through effective primary prevention policies <sup>(5)</sup>, thereby sparing families the pain of miscarriages, terminations, and stillbirths.

### **NTDs and social determinants of health**

The primary prevention of NTDs is crucial to improve health equity and tackling social determinants of health. The prevalence of NTDs is not equally distributed throughout the world with low- and middle-income countries experiencing much higher rates <sup>(5)</sup>. Consequently, the communities which experience the highest rates of Spina Bifida and other NTDs are also the same communities who experience less availability and accessibility to necessary health services, with fatal consequences when medical intervention would otherwise have ensured survival <sup>(5)</sup>. Policies for the primary prevention of NTDs must consider the socio-economic factors affecting nutrition and maternal health.

### **What is food fortification?**

Food fortification is a process where micronutrients are added to commonly consumed foods to improve nutritional quality. Policies that incentivise or make food fortification mandatory are commonly used to address public health concerns arising from a micronutrient deficiency, for example iron or vitamin B9 deficiency <sup>(6)</sup>. Successful fortification policies have been implemented in many countries through public-private-civic partnerships <sup>(7)</sup>. These policies have proven to be extraordinarily cost-effective, with the cost of implementation being minuscule compared to the monetary savings for the public health system <sup>(8)</sup>. In addition, food fortification is a highly effective policy when viewed in the context of socio-economic determinants of health. By adding the necessary micronutrients into foods which are affordable and widely consumed, food fortification reaches persons and communities who don't have consistent access to other forms of preventative healthcare services <sup>(5)</sup>. By doing so, food fortification of staple foods with vitamin B9 advances health equity and improves maternal and infant health. Food fortification is a safe

and cost-effective policy that has proven its efficacy in reducing the rates of NTDs wherever implemented<sup>(5)</sup>.

Yet, despite the clear evidence that vitamin B9 fortification is the most effective policy for the primary prevention of Spina Bifida and other NTDs, many countries have not yet taken the necessary steps to implement it. Therefore, there is a big opportunity and need to expand the policy of mandatory food fortification worldwide.

### **The Economic benefits of food fortification of staple foods with folic acid**

Prevention of NTDs through a comprehensive health strategy including staple food fortification, supplementation, and nutrition education has been shown to be an economically effective strategy. Costs associated with implementing policies for the primary prevention of NTDs dwarf when compared to both direct and indirect costs of NTDs as experienced by people with NTDs, their families and caregivers as well as the overall cost of care for healthcare payers<sup>(8)</sup>. Access to healthcare is a human right, and primary prevention policies do not, and must not, replace efforts to strengthen healthcare systems and improve access, in particular for persons with disabilities. However, considering the unequal distribution of NTDs in the world and the socio-economic factors which influence this inequality, the estimated cost-savings already experienced in countries which have implemented mandatory fortification of staple foods with vitamin B9<sup>(10)</sup> need to be replicated globally as healthcare payers across the world struggle with rising healthcare costs.

### **Stakeholders:**

Different stakeholders need to be involved for the primary prevention of NTDs<sup>(7)</sup>. Food fortification involves the input of various stakeholders from the public, private and civic sectors. Awareness raising on NTDs among all stakeholders and the positive role which fortification plays in reducing their prevalence is essential for the implementation of fortification policies.

#### ***Public-Private-Civic sectors***

Progress in reducing risks for NTDs requires a dynamic collaboration between public-private-civic sectors. Public sector includes international organisations and their agencies, national governments agencies, entities and policy makers as well as academic institutions. Private sector in the context of fortification denotes stakeholders such as millers, equipment and flour production companies, wheat traders, baker organisations, and other affiliated businesses. The civic sector plays a vital role in connecting these different stakeholders, raising awareness of NTDs and facilitating rights-based policies. It is especially important to include SBH associations in these collaborations to ensure that these policies do not only reduce the rates of NTDs but also combat the stigma experienced by the SBH community.

#### ***International Federation for Spina Bifida and Hydrocephalus***

For more than 15 years, the International Federation for Spina Bifida and Hydrocephalus (IF) has worked together with SBH associations, flour millers, governments, vitamin and mineral suppliers, international organisations, and academic institutions to make fortification of wheat and maize flour a reality. This is a good example of an effective public-private-civic partnership.

IF is one of the stakeholders who brings together the milling industry, governments, and development partners to support the implementation of national flour fortification programs and aims to improve the nutritional quality of wheat and maize flour. Activities include providing training to millers, regulatory inspectors, program managers, and regional and international agencies on quality assurance and quality control, monitoring and surveillance, cost-benefit analyses, and fortification advocacy.

### ***World Health Organization***

The World Health Organization (WHO) recommends that pregnant women take supplements with iron and vitamin B9<sup>(9)</sup>. It further endorses that all women of reproductive age should have sufficient levels of folate to achieve the greatest reductions of NTDs<sup>(2)</sup>. In the 2010 World Health Assembly Resolution on Birth Defects, the importance of birth defects as a cause of stillbirths and neonatal mortality was recognised together with the role of preventable factors such as inadequate nutrition. The resolution called on Member States to raise awareness of birth defects, increase coverage of prevention measures including supplementation of vitamin B9, and develop expertise and capacity on the prevention of birth defects. Despite this, only a quarter of all global cases of preventable Spina Bifida and other NTDs are being prevented<sup>(5)</sup>. The scientific evidence overwhelmingly supports that just encouraging the use of vitamin B9 supplements is not sufficient to lower the rates of preventable Spina Bifida and other NTDs<sup>(5)</sup>. Furthermore, the WHO has in recent guidelines put forward recommendations for the fortification of staple foods such as rice<sup>(10)</sup> and flour<sup>(11)</sup> with folic acid to reduce the occurrence of pregnancies affected by NTDs.

### ***United Nations Food and Agricultural Organization***

The WHO, together with the United Nations Food and Agricultural Organization (FAO), published 'Guidelines on food fortification with micronutrients' which provides guidance on how to implement policies on fortification, including vitamin B9<sup>(6)</sup> in 2006. The benefits of the fortification of vitamin B9 in staple foods is widely acknowledged in the context of economic and social development in low-income countries.

### ***European Union***

In July 2020, the European Commission published a 'Guidance Note on Food Fortification in development cooperation' where food fortification is acknowledged to be a proven and cost-effective strategy that improves public health as well as health and economic resilience of communities<sup>(12)</sup>. Spina Bifida and other NTDs due to low folate levels are not only a challenge for low-income countries but is a universal challenge. Food fortification with vitamin B9 has been very successful in lowering the rates of NTDs in high income countries such as the USA<sup>(13)</sup>. Yet despite this there is currently no EU Member State that implements mandatory food fortification with vitamin B9<sup>(14)</sup>.

### ***Sustainable Development Goals***

Food fortification is essential for sustainable development and for the achievement of Sustainable Development Goals (SDGs). Food fortification advances several objectives of the SDGs, including SDG 2 which includes target 2.2 which aims to combat all forms of malnutrition

and address the nutritional needs of adolescent girls, pregnant and lactating women. Food fortification also contributes to the attainment of SDG 3 which includes target 3.2 that aims to combat preventable deaths of infants and reduce neonatal mortality.

The SDGs are for all Member States of the UN, regardless of their income levels. Calling for mandatory fortification of staple foods with Vitamin B9 (folic acid) for all countries is necessary to achieve the SDGs.

### **Primary prevention and the rights of persons with disabilities**

Primary prevention programmes have also been addressed in the context of the rights of persons with disabilities. As outlined by the United Nations in a 2017 report,<sup>(15)</sup> primary prevention is an essential component of public health policy. The primary prevention of NTDs, however, is not a substitute for the creation of accessible and inclusive societies. Persons with SBH and their families have the right to accessibility, inclusivity, and high quality and affordable services for the full realisation of their human rights as per the UN Convention on the Rights of Persons with Disabilities (UNCRPD). Funds and initiatives intended to enable inclusion and accessibility for persons with disabilities should not be used for the primary prevention of disabilities such as NTDs including Spina Bifida.

Disability is a part of the spectrum of the human experience; and both primary and secondary prevention in the context of NTDs including Spina Bifida must be viewed from a right-based perspective and in adherence with the UNCRPD. All state parties to the UNCRPD have committed themselves to implement, advance, and protect the rights of persons with disabilities, including “Full and effective participation and inclusion in society” as per article 3(3) UNCRPD. People with Spina Bifida and other forms of NTDs and their families experience discrimination, inaccessibility, and exclusion in various aspects of life.

Awareness and advocacy for the primary prevention of NTDs risks stigmatising people with NTDs including Spina Bifida and their families if not designed and implemented from a rights-based perspective. Successful primary prevention policies must look towards article 8(b) UNCRPD and seek to “To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life”. Policies for the primary prevention of NTDs including Spina Bifida must be designed with the input of the SBH community and implemented in a way which does not use stigmatising language or images nor contradicts or hinders the full realisation of the rights of people with NTDs such as Spina Bifida as outlined in the UNCRPD.

### **The need for global action**

Reducing the prevalence of preventable Spina Bifida and NTDs is essential to reach the ambitions of the international community as laid out in the 2010 WHA resolution on birth defects, the SDGs and their targets, and more. It is essential to reduce neonatal mortality, address micronutrient deficiencies, and end preventable deaths of infants. Primary prevention of NTDs through food fortification with vitamin B9 is a successful, cost-effective, and safe public health initiative.

It is the most effective policy to tackle the social determinants of health. It is a safe and cost-efficient policy that reaches all of society by circumventing the numerous barriers marginalising people and communities from other forms of preventative health actions. It is a necessary public health action for all regions and countries. The SDGs are relevant goals for every country; vitamin B9 fortification needs to be acknowledged and addressed as a global goal.

The policies implemented in the decades since the link between low vitamin B9 levels during pregnancy and the development of NTDs have been established, demonstrate that mandatory fortification of staple foods with vitamin B9 is the most effective action to reduce the rate of preventable Spina Bifida and other NTDs. Several countries have implemented such policies with great success, but what is needed is a global action to make primary prevention of NTDs through mandatory fortification of staple foods with vitamin B9 a reality across the world. The need for an effective, rights-based approach for the primary prevention of Spina Bifida and other NTDs is paramount. To achieve this goal, IF presents the following recommendations for an international call to action for the primary prevention of Neural Tube Defects.

**IF calls on all relevant stakeholders to support a global action that includes the following recommendations:**

- To develop and implement mandatory fortification programs of vitamin B9 in staple foods for the prevention of NTDs,
- To make mandatory fortification of staple foods with vitamin B9 a global priority,
- To raise awareness of NTDs, combat stigma associated with them and of effective rights-based prevention strategies which respect the dignity and rights of persons with disabilities among all relevant stakeholders including government officials, health professionals, civil society and the public,
- To ensure that mandatory fortification programs adhere to international standards and guidelines,
- To promote and strengthen primary prevention of NTDs through food fortification by involving all relevant actors. In particular, ensuring that the development of the policies are done in accordance with article 4(3) of the UN Convention on the Rights of Persons with Disabilities by consulting persons with disabilities, including persons with NTDs, and their representative organisations in the development of policies relevant to them, including policies for the primary prevention of NTDs.

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## ABOUT IF

Spina Bifida and Hydrocephalus (SBH) are complex health conditions which develop during the first four weeks of pregnancy as a result of the neural tube and spine not developing correctly. 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. With global coverage, IF's mission 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.

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