

FORTIFICATION IMPROVES LIVES

Dr. Papatya Alkan Genca

Board Member

International Federation for Spina Bifida and Hydrocephalus

Türkiye Spina Bifida Derneği

IAOM EURASIA Conference & Expo August 31, 2023



“Each of us can
make a difference.
Together we make
change.”





Türkiye
Spina Bifida
Derneđi



What is Spina Bifida?



<https://www.youtube.com/watch?v=QoKqHza9rL0&t=16s>

Difference
“faces” of
spina bifida
and
hydrocephalus



Difference
“faces” of
spina bifida
and
hydrocephalus



RESEARCH ARTICLE

Describing the **Prevalence** of Neural Tube Defects Worldwide: A Systematic Literature Review

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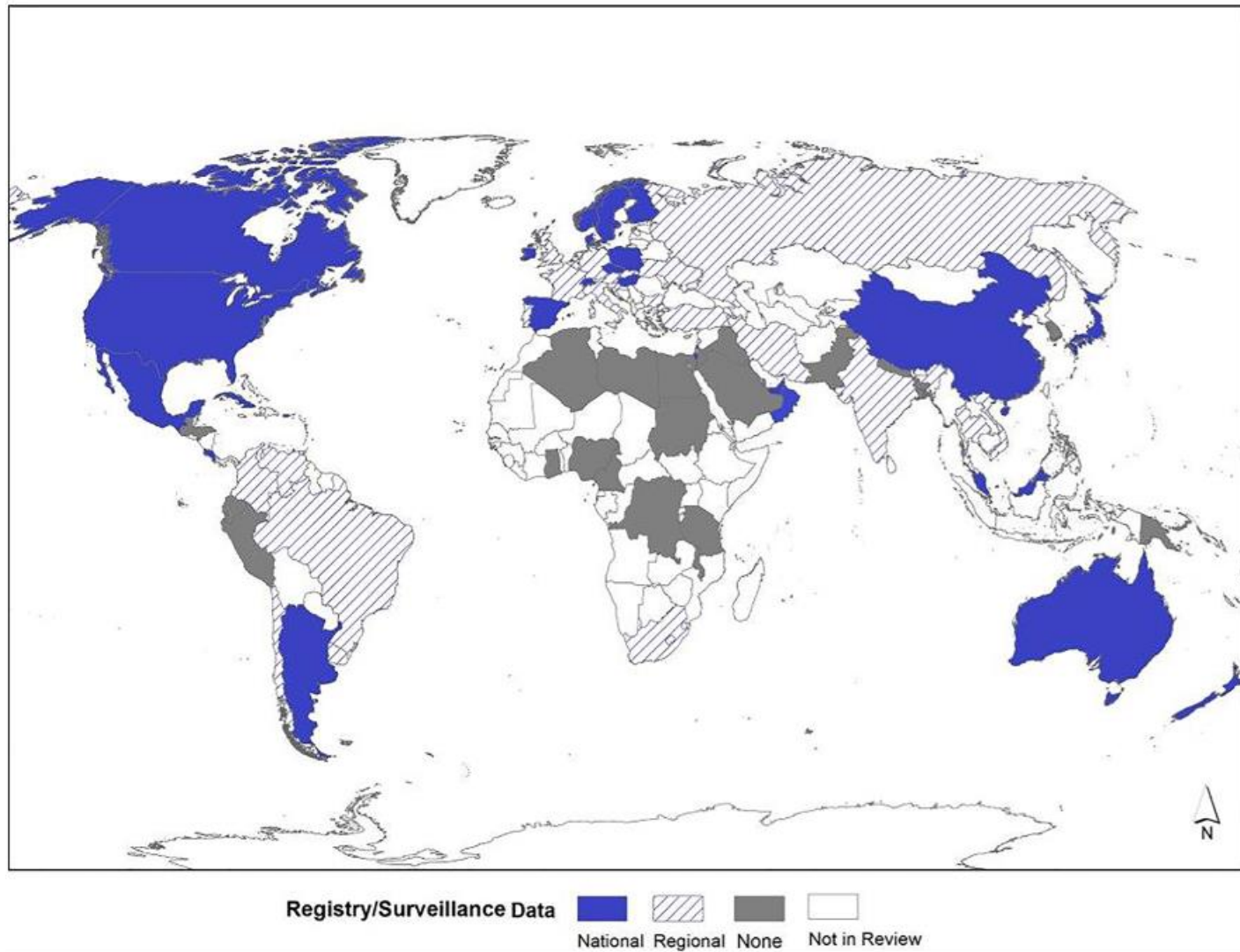
Abstract

Background

Folate-sensitive neural tube defects (NTDs) are an important, preventable cause of morbidity and mortality worldwide. There is a need to describe the current global burden of NTDs and identify gaps in available NTD data.

Methods and Findings

We conducted a systematic review and searched multiple databases for NTD prevalence estimates and abstracted data from peer-reviewed literature, birth defects surveillance registries, and reports published between January 1990 and July 2014 that had greater than 5,000 births and were not solely based on mortality data. We classified countries according to World Health Organization (WHO) regions and World Bank income classifications. The initial search yielded 11,614 results; after systematic review we identified 160 full text manuscripts and reports that met the inclusion criteria. Data came from 75 countries. Coverage by WHO region varied in completeness (i.e., % of countries reporting) as follows: African (17%), Eastern Mediterranean (57%), European (49%), Americas (43%), South-East Asian (36%), and Western Pacific (33%). The reported NTD prevalence ranges and medians for each region were: African (5.2–75.4; 11.7 per 10,000 births), Eastern Mediterranean (2.1–124.1; 21.9 per 10,000 births), European (1.3–35.9; 9.0 per 10,000 births), Americas (3.3–27.9; 11.5 per 10,000 births), South-East Asian (1.9–66.2; 15.8 per 10,000 births), and Western Pacific (0.3–199.4; 6.9 per 10,000 births). The presence of a registry or surveillance system for NTDs increased with country income level: low income (0%), lower-middle income (25%), upper-middle income (70%), and high income (91%).



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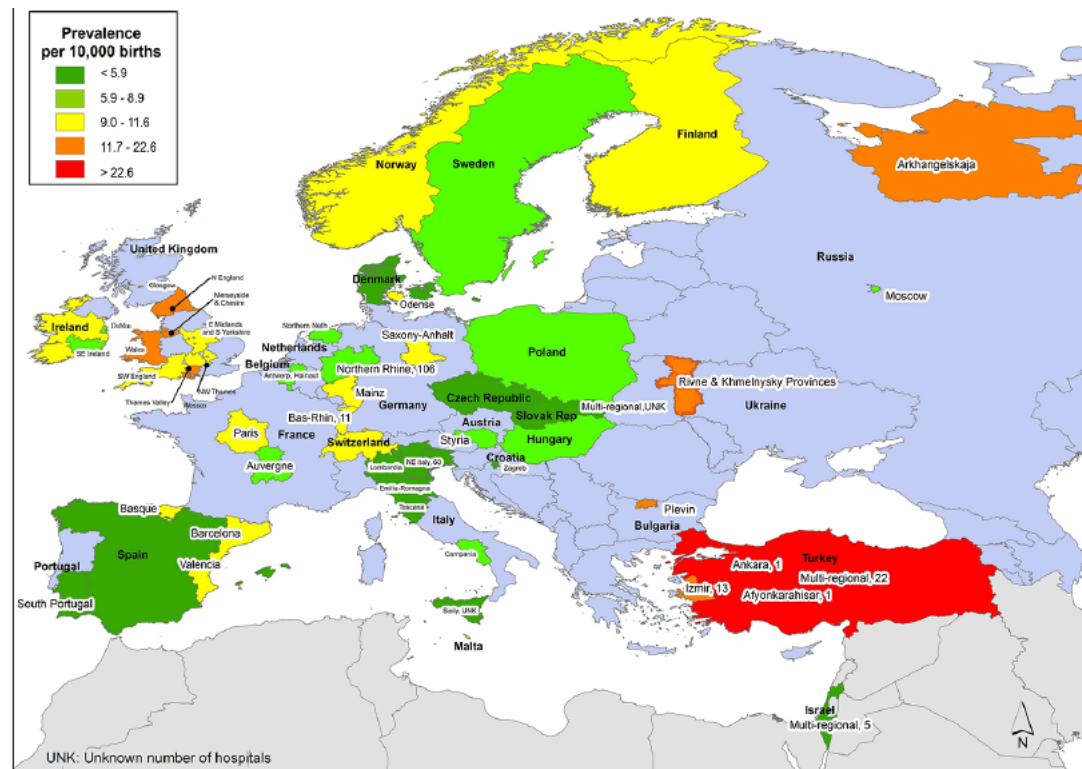


Fig 7. European Region Neural Tube Defects Prevalence Estimates (Location, Number of Hospitals). The majority of data from the European region was population based. All data based on hospital studies from regions is indicated with the number of hospitals. If there were national or regional data available for more than one NTD, the entire country or region was filled-in based on the prevalence per 10,000 births. In instances where multiple prevalence estimates were available at the national level, the prevalence reported by the study/report with the least risk-of-bias was selected. Countries colored in grey are not a part of the World Health Organization region. A national study from Israel is not represented on this map since it only provided prevalence by ethnicity. Shapefile reprinted from <http://www.gadm.org> under a CC BY license, with permission from Global Administrative Areas and Dr. Robert Hijmans.

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Preventing birth defects, saving lives, and promoting health equity: an urgent call to action for universal mandatory food fortification with folic acid

Vijaya Kancharla, Lorenzo D Botto, Laura A Rowe, Nathan A Shlobin, Adrian Caceres, Anastasia Arynchyna-Smith, Kathrin Zimmerman, Jeffrey Blount, Zewdie Kibryisfaw, Kemal A Ghotme, Santosh Karmakar, Graham Fieggen, Sylvia Roozen, Godfrey P Oakley Jr, Gail Rousseau, Robert J Berry

July 20, 2021 marked the 30th anniversary of the publication of the landmark trial by the British Medical Research Council showing unequivocally that maternal intake of folic acid (vitamin B₉) starting before pregnancy prevents most cases of infant spina bifida and anencephaly—two major neural tube defects that are severe, disabling, and often fatal. Mandatory food fortification with folic acid is a safe, cost-effective, and sustainable intervention to prevent spina bifida and anencephaly. Yet few countries implement fortification with folic acid; only a quarter of all preventable spina bifida and anencephaly cases worldwide are currently avoided by food fortification. We summarise scientific evidence supporting immediate, mandatory fortification with folic acid to prevent the development of spina bifida and anencephaly. We make an urgent call to action for the World Health Assembly to pass a resolution for universal mandatory folic acid fortification. Such a resolution could accelerate the slow pace of spina bifida and anencephaly prevention globally, and will assist countries to reach their 2030 Sustainable Development Goals on child mortality and health equity. The cost of inaction is profound, and disproportionately impacts susceptible populations in low-income and middle-income countries.

Background

Spina bifida and anencephaly are common neural tube defects. Anencephaly is fatal, and open spina bifida, also known as myelomeningocele, is treatable but not curable, and is associated with an increased risk of child mortality. Many individuals living with spina bifida suffer permanent disability and chronic physical and psychological health complications, requiring lifelong surgical and medical care. Surgical care for spina bifida is expensive, complex, and scarce in many countries due to a shortage of specialised surgeons and multi-disciplinary care teams.

An analysis published in 2018 estimated that at least 214 000–322 000 pregnancies worldwide are affected by spina bifida and anencephaly annually, at an average prevalence of about 20 cases per 10 000 births.¹ The burden corresponds to one in every 500 births globally. In low-income and middle-income countries, the prevalence exceeds one in every 100 births. Annually, about 60 000 affected pregnancies are electively terminated after prenatal diagnosis, and another 60 000 result in stillbirths.¹

Of the few known causes of spina bifida and anencephaly, the most predominant is insufficient concentration of folate in the mother before and during early pregnancy.² Diet alone is insufficient to provide the recommended daily intake of folic acid, because a considerable amount of food folate is lost during food processing and cooking.³ In addition, food folate has poorer bioavailability than folic acid.⁴ Folic acid supplement pills are recommended along with a healthy diet. Folic acid is essential for the development of the neural tube in the first 4 weeks of pregnancy, but given that half of all pregnancies worldwide are unplanned,⁵

most women are unaware of their pregnancies during this critical window and might not take the recommended intake of folic acid. Health-care providers can generally only prescribe prenatal vitamin supplements when the pregnancy is discovered, typically after the fourth completed week of gestation, at which point it is too late to prevent spina bifida and anencephaly. Supplement programmes also require sustained external funding and continuous educational campaigns; they typically depend on individual behaviours and have low adherence rates.⁶

The solution is to provide adequate folic acid to women of reproductive age in a way that is timely, effective, equitable, and economical; large-scale food fortification meets all these criteria.⁷

Safety and benefits of folic acid food fortification

There is strong evidence of the safety of providing folic acid through the fortification of staple foods.⁸ Contrary to concerns raised in the 1970s, folic acid does not mask anaemia caused by vitamin B₁₂ deficiency.⁹ Evidence of potential adverse effects of circulating unmetabolised folic acid from supplemental folic acid is inconclusive, with no clear evidence pointing to adverse metabolic and clinical effects of high intake.¹⁰ Similarly, claims of potential risks related to cancer, cognitive impairment, diabetes-related disorders, thyroid disease, and hypersensitivity-related outcomes have not been validated.⁸ By contrast, food fortification with folic acid is highly effective in safely preventing spina bifida and anencephaly, as proven by multiple studies from different countries.^{11,12}

Fortified staple foods have a wide reach. Folic acid consumption, achieved through fortification, would not be limited to people (or countries) who can afford vitamin supplements or receive adequate preconception or

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Figure: Countries with mandatory large-scale food fortification policies for cereal grain achieving optimal prevention of folic acid-preventable spina bifida and anencephaly in the year 2020. Countries in green provide daily intake of folic acid (>150 µg/day) through mandatory cereal grain (ie, wheat flour, maize flour, or rice) fortification to effectively prevent folic acid-preventable spina bifida and anencephaly. The figure is based on data from the Global Fortification Data Exchange. The adequate daily intake is calculated on the basis of the amount of folic acid fortification in cereal grains (µg/g), the estimated amount (g/day) of cereal grains per person available for consumption, and the proportion of cereal grain that is produced in large-scale industrial mills and fortified with folic acid.

WHY SHOULD YOU CARE

The Global Gap

An additional 82% of birth defects of the brain and spine¹ and 34% of global anemia cases² could still be **prevented** through adequate intake of iron and folic acid.

¹ <https://www.ncbi.nlm.nih.gov/pubmed/30070772>

² <https://www.ncbi.nlm.nih.gov/pubmed/30997493>



THE ROAD TO EFFECTIVE PREVENTION



THE ROAD TO EFFECTIVE PREVENTION



INTERNATIONAL FEDERATION
FOR SPINA BIFIDA AND HYDROCEPHALUS

Consultative status special category with Economic and Social Council of the United Nations
Participatory status, Council of Europe

IF POLICY STATEMENT ON PREVENTION OF NEURAL TUBE DEFECTS AND MANDATORY FOOD FORTIFICATION

Adopted by the IF Annual General Meeting
on 28 June 2005 in Minneapolis

IF calls for action to:

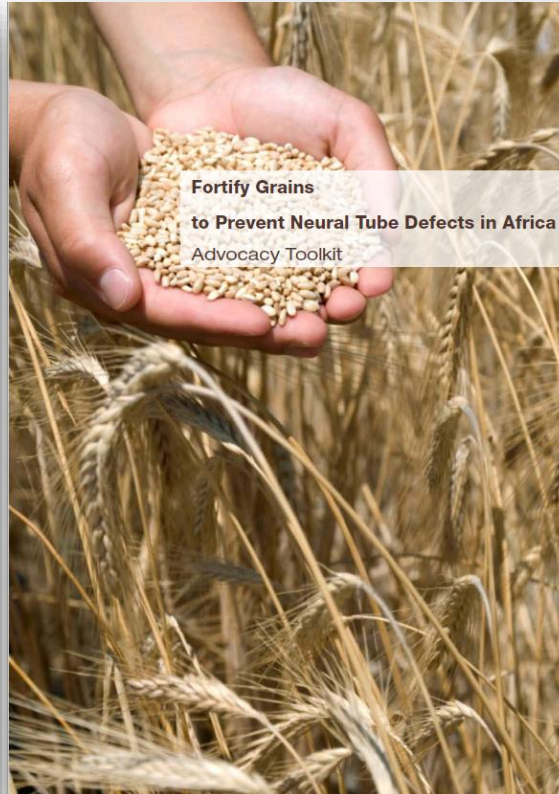
1. Promote the health benefits of the vitamin folic acid.
2. Ratify a policy calling on all countries to fortify staple food with the vitamin folic acid to reduce the incidence of neural tube defects (NTDs).
3. Encourage further research into the prevention of neural tube defects (including spina bifida).

Primary Prevention and folic acid

Maternal periconceptional use of folic acid has been found to reduce the risk of both recurrent and occurrent NTDs (Locksmith and Diff, 1998; Watkins, 1998; Czeizel et al. 1999). This reduction occurs both in regions of high NTD rates and in regions of low NTD rates (Berr et al. 1999).¹ Lumley et al. found that reductions of up to 70% can be achieved with the correct dosage.²

Folic acid is the synthetic form of the vitamin folate, which is naturally found in foods. It is a simple, inexpensive supplement which reduces the incidence of NTDs in the fetus if taken by women prior to conception and for the first three months of pregnancy.

The recommended folate intake is 0.6mg per day³, but as a normal diet cannot provide this level, an extra 0.4mg per day is required through folic acid supplements. This should be taken for at least a month before becoming pregnant and for the first three months of pregnancy.



Fortify Grains
to Prevent Neural Tube Defects in Africa
Advocacy Toolkit



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^[1].

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^[2] 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^[3]. 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^[4]. 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



SEVENTY-SIXTH WORLD HEALTH ASSEMBLY
Agenda item 16.5

WHA76.19
30 May 2023

Accelerating efforts for preventing micronutrient deficiencies and their consequences, including spina bifida and other neural tube defects, through safe and effective food fortification

The Seventy-sixth World Health Assembly,

Having considered the consolidated report by the Director-General;¹

Recalling resolutions WHA39.31 (1986) on prevention and control of iodine disorders; WHA45.33 (1992) on national strategies for prevention and control of micronutrient malnutrition; WHA58.24 (2005) on sustaining the elimination of iodine deficiency disorders; WHA65.6 (2012) on comprehensive implementation plan on maternal, infant and young child nutrition; and WHA68.19 (2015) on outcome of the Second International Conference on Nutrition, which promote food fortification as a mechanism to prevent micronutrient deficiencies and birth defects associated with nutritional deficiencies;

Recalling also resolution WHA63.17 (2010) on birth defects, which requested the Director-General to support Member States in developing national plans for implementation of effective interventions to prevent and manage birth defects within their national maternal, newborn and child health plan, and food fortification strategies, among others, for the prevention of birth defects, and promoting equitable access to such services; and urged Member States to increase coverage of effective prevention measures, including folic acid supplementation;

Recognizing that micronutrient deficiencies are a public health concern as they constitute a risk factor for many diseases, and they may lead to increasing morbidity and mortality rates; and that the latest estimates indicate that 372 million preschool children and 1.2 billion women of reproductive age worldwide are at risk of at least one micronutrient deficiency;

EXAMPLE - SMARTER FUTURES

SMARTER FUTURES' UNIQUE MODEL

SMARTER FUTURES
A BRIEF OVERVIEW

Smarter Futures is a unique public-private-civic partnership, focused specifically on Africa, that provides technical support to grain millers, governments, vitamin and mineral suppliers, international organizations, and academic institutions to make fortification of wheat flour, maize flour, and rice a reality.

As of 2020, Smarter Futures partners include the Food Fortification Initiative (FFI) as the main implementing partner, the International Federation of Spina Bifida and Hydrocephalus (IF), Nouryon (formerly AkzoNobel), Helen Keller International (HKI), the World Food Program (WFP), Mühlenchemie, Bühler, Nutrition International (NI), the Global Alliance for Improved Nutrition (GAIN), and the Dutch Ministry of Foreign Affairs.

Smarter Futures does not itself invest large programme resources but supports and strengthens the efforts of its network partners. Current Smarter Futures funding from the Dutch Government and from GAIN runs for 2018-2021.



Photo: Rod Waddington

OUR GOALS AND UNIQUE CONTRIBUTION

Smarter Futures has two main goals:

1. Improve the health of all, particularly women of childbearing age, adolescents girls, and children across Africa through the fortification of wheat flour, maize flour, and rice with essential vitamins and minerals, notably iron and folic acid, through the provision of technical support, and
2. Work with partner agencies in similar countries, regions, and across similar domains while simultaneously ensuring complementarity of approaches.

Smarter Futures is unique in that it:

1. Brings together key stakeholders (i.e. government officials, millers, and civil society actors) involved in grain fortification and stimulates exchanges at the regional level, providing opportunities to share experiences and motivate countries to follow the examples and progress achieved by other countries.
2. Places a particular focus on the involvement and inclusion of civil society actors such as disability groups, consumer associations, physicians and neurosurgeons, and parent associations related to spina bifida and hydrocephalus through the involvement and actions of International Federation of Spina Bifida and Hydrocephalus (IF).

As project holder, IF is driven by its mission to decrease the birth prevalence of spina bifida and hydrocephalus through primary prevention, especially fortification of folic acid, to improve the quality of life for those living with these disabilities. IF represents Members Associations in 14 countries in Africa, notably Algeria, Egypt, Ethiopia, Ghana, Kenya, Malawi, Morocco, Nigeria, South Africa, Sudan, Tanzania, Uganda, Zambia and Zimbabwe. These associations, healthcare professionals, and other interested partners provide advocacy, primary and secondary prevention activities in the countries where they are based.

smarterfutures.net



PUBLIC SECTOR

Agencies of the United Nations, government agencies and other national entities, non-governmental organizations and academic organizations



PRIVATE SECTOR

Millers, equipment and flour-product companies, wheat traders, baking organizations, and other affiliated businesses

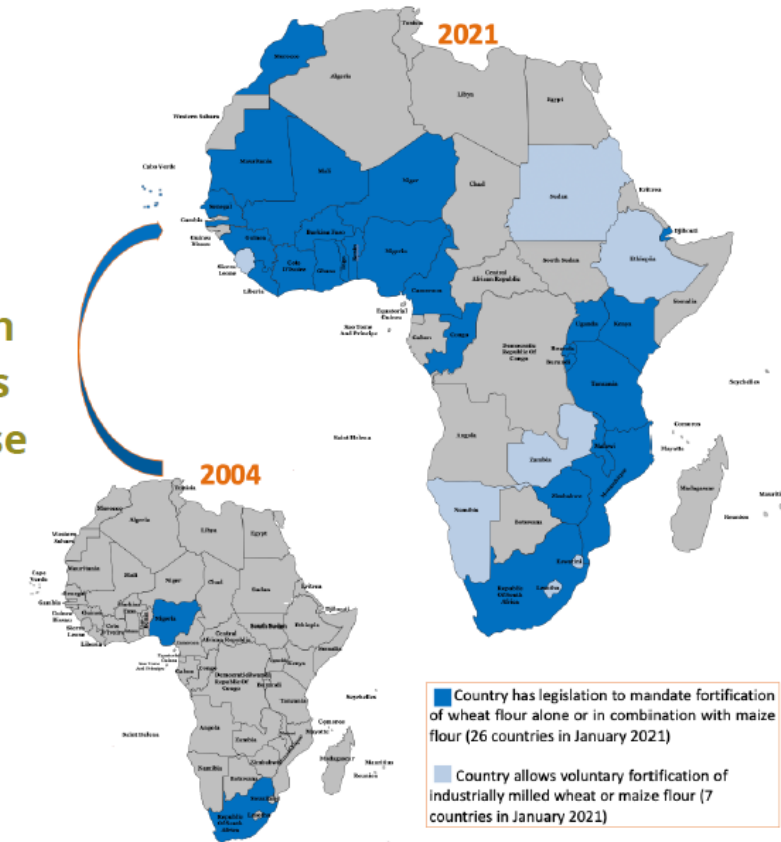


CIVIC SECTOR

Patient, parent, and professional organizations representing the civic domain

Fortifying wheat and maize flour as well as rice, which are important staples in Africa, with iron, folic acid and other vitamins and minerals provides adolescent girls and women with these essentially important micronutrients well before pregnancy occurs.

Flour Fortification in Africa: 17 Years of Progress





MILLERS YOU ARE THE ONLY ONES WHO CAN FORTIFY FLOUR!!

**Fortifying flour with folic acid
is a good solution!**



SUMMARY

- Neural Tube Defects are a serious health concern due to prevalence rates
- Fortifying flour with folic acid is an effective way to prevent NTDs
- Countries that made fortification mandatory have experienced between 31 and 78% reductions in NTD prevalence
- Countries can avert millions of dollars in healthcare expenditures when spina bifida is prevented
- Millers are **key partners** in preventing Neural Tube Defects!

USEFUL WEBSITES

www.SmarterFutures.net

www.FFInetwork.org

www.IFglobal.org

www.spinabifida.org.tr



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



Türkiye _____
Spina Bifida
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