### POLICY BRIEF May 2016

# What are Neural Tube Defects?

Neural tube defects (NTDs) are serious birth defects of the brain or spinal cord that may cause lifelong disability or infant death. They occur when the neural tube fails to close properly during the early stages of fetal development.

**Examples:** Anencephaly, Encephalocele, Spina Bifida

**Implications:** Learning difficulties, physical impairment, neurological problems

**Prevalence:** 2,500 infants in the U.S. are born with NTDs every year [1]

**Treatment:** There is no cure for NTDs, and treatment varies based on type and severity

Adequate folic acid intake can decrease the risk of NTDs.

# FOLIC ACID SUPPLEMENTATION IN CHILDBEARING YEARS: MISSED OPPORTUNITIES

Neural tube defects are the second most common cause of serious birth defects in the United States. About 2,500 infants are born with these devastating defects every year in the US [1]. Due to the complex care for those affected, yearly hospital costs associated with neural tube defects are over \$85 million [1]. The most effective way to prevent neural tube defects is surprisingly simple – taking a daily folic acid supplement prior to pregnancy can reduce the risk of a woman giving birth to an infant with neural tube defects by 70% [1]. Thus, since 1992 the Centers for Disease Control and Prevention recommends all women of childbearing age take 400 micrograms (mcg) of folic acid daily. Unfortunately, over two-thirds of US women of childbearing age report not taking a folic acid supplement prior to pregnancy. This is a huge portion of the population at increased risk of having a baby with a neural tube defect. This brief urges policymakers to help decrease these numbers by (1) expanding Medicaid coverage of folic acid supplements and (2) improving folic acid supplement education, with a focus on behavior change.

Before exploring solutions, it is crucial to understand who is at greatest risk for inadequate folic acid supplementation and why. Surveys [1, 2] show that women least likely to take a folic acid supplement prior to pregnancy include non-White and lower socioeconomic status women. Since non-White, lower- income women are already at higher risk for poor birth outcomes, their low rates of folic acid supplementation are particularly concerning. Efforts should especially focus on improving supplementation among these populations.

Some of the most common reasons women report for not taking a folic acid supplement prior to their pregnancy are as follows [1]:

- 1. The pregnancy was unplanned (61% of women)
- 2. They did not realize a folic acid supplement was needed (41% of women)
- 3. A folic acid supplement was too expensive (7% of women)

Evidently, most women not taking a folic acid supplement either do not plan on becoming pregnant and/or are unaware of folic acid recommendations. Thus, strategies to increase folic acid supplementation must include a strong education component and must occur prior to when a woman plans on becoming pregnant.

### **PROBLEMS**

Several factors hinder efforts to increase folic acid supplementation prior to pregnancy. First, about 50% of all pregnancies in the U.S. are unplanned [3]. Not planning on becoming pregnant is a very common reason postpartum women report for not having taken a folic acid supplement before pregnancy [1]. Unfortunately, once a woman realizes she is pregnant, it is too late to start taking a folic acid supplement to prevent birth defects. Thus, the large number of unplanned pregnancies is a major factor behind low folic acid supplementation rates in the U.S.

Second, folic acid supplements are not made readily accessible to all women prior to pregnancy. Doctors report prescribing folic acid supplements during only 7% of preventive care visits for non-pregnant women [4]. While doctors are much more likely to prescribe folic acid to their already-pregnant patients, this is often too late to help prevent neural tube defects. The vast majority of non-pregnant women, however, are not being offered a prescription for folic acid.

Compounding all these problems is the lack of preconception counseling provided by physicians. Only one-third of women report receiving education before pregnancy from their doctor on how to have a healthy pregnancy and birth. Thus, most non-pregnant women (70%) are not hearing about the importance of folic acid supplements from their healthcare providers [5]. Sadly, research shows that the women most in

need of folic acid education - lower socioeconomic, Hispanic, and Black - are also the least likely to receive this counseling from their doctor prior to pregnancy. Unfortunately, these missed opportunities to prescribe or to simply discuss folic acid supplements prior to pregnancy leave far too many infants unprotected from the devastating effects of neural tube defects.

In 1992, in an effort to decrease the incidence of neural tube defects, the U.S. Public Health Service recommended that all women capable of becoming pregnant consume 400 mcg of folic acid daily. By 1998, the U.S. mandated folic acid fortification of enriched grain products. Immediately after mandatory fortification, the birth prevalence of neural tube defects cases declined and has remained relatively stable since post-fortification. The number of births occurring annually without neural tube defects that would otherwise have been affected is approximately 1,326 [7].

While folate levels have improved since fortification began in 1998, there are still subpopulations who have higher prevalence rates of neural tube defects that may not be receiving the full benefit of fortified grain products. For example, Mexican American women have lower folic acid intake than non-Hispanic white women and are 21% more likely to have a baby affected by a neural tube defect than non-Hispanic white women [8]. Thus, in early 2016 the Food and Drug Administration (FDA) gave manufacturers permission to add folic acid to corn masa flour used to make tortillas and tamales [9]. Preliminary modeling studies

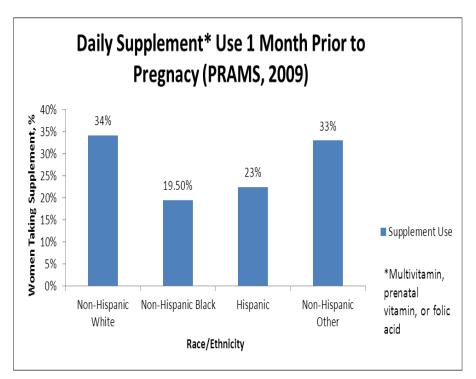
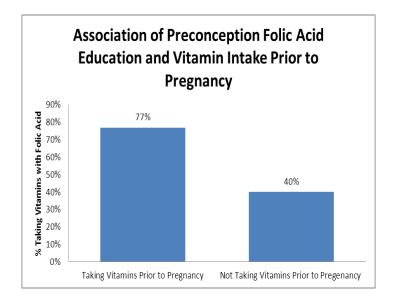


Figure 1: Supplement Use in the United States 1 Month Prior to Pregnancy by Race/Ethnicity - PRAMS (2009) [6]



**Figure 2:** Association of Preconception Folic Acid Education and Vitamin Intake Prior to Pregnancy in the U.S. [1]

Counseling on folic acid was associated with greater vitamin use regardless of whether a woman's pregnancy was intentional or non-intentional. Data show that health care provider recommendation is the single greatest reason women would start taking a multivitamin with folic acid. There is also evidence that brief, 30–60 second folic acid counseling directed to all women of childbearing age by clinicians has been effective in increasing folic acid use. [1]

show that the fortified corn masa flour promises the greatest benefit for non-Hispanic white women with low acculturation. However, research also found that non-Hispanic black women actually had the lowest daily folic acid intake of all groups studied [10]. Clearly, racial and ethnic disparities still remain and therefore supplementation is crucial.

### RECOMMENDATIONS

### 1. Expand Medicaid Coverage of Folic Acid Supplements

A health care provider's prescription for folic acid is another key for unlocking actual behavior change. While a prescription is not typically needed for vitamin or mineral supplements, providing prescriptions has been shown to improve compliance with taking supplements. For example, women who were given an electronic prescription for calcium were over twice as likely to still be taking calcium supplements after six months, compared to those who just received counseling [11]. A prescription can be the tangible connection between a woman's awareness of the importance of folic acid and her actually taking a supplement. Unfortunately, most (74%) of State Medicaid programs do not cover a folic acid supplement without going through prior authorization.

One reason reported by women for not taking a folic acid supplement before pregnancy is the cost of the supplement [1]. This is not surprising since lower-income/socioeconomic-status women are among those least likely to take a folic acid supplement [1, 2]. Because most State Medicaid programs do not cover folic acid, some of the most high-risk, vulnerable women cannot obtain folic acid supplements through Medicaid. It is crucial that *all* State Medicaid programs include folic acid supplements on their preferred drug lists, thus improving access for lower-income women.

# 2. Support the Development and Utilization of Technology-based Education

Even with access to folic acid supplements, there is still a need for education and counseling to increase early supplementation. Studies have shown that women who receive information on supplementation before pregnancy are more likely to begin taking folic acid prior to conception than those who do not [12]. Clearly, it is important to find innovative ways to reach women and provide them with the necessary educational tools before they see a physician for their pregnancy.

Applications for mobile devices and texting-based programs have shown to be a promising tool in the field of public health.

One such program is the text4baby initiative. text4baby delivers health messages through text messaging to women during their pregnancy and through their baby's first year of life. This has been shown to be an effective way to reach women. In a recent study, 92% of all women surveyed who signed up for Text4baby read all of the text messages delivered to them during the course of the study and 88% planned to continue to participate in the program even after the study ended [13]. Unfortunately, Text4baby is not designed for women who have not yet become pregnant, and there is minimal educational messaging on folic acid after pregnancy. As behavior change interventions delivered via text messaging have been widely accepted and effective [14] particularly among minority groups [15], it is important to expand support and funding for technology-based education to give all women of childbearing age access to folic acid supplementation information.

## 3. Extend the WIC Certification Period for Postpartum Non-Breastfeeding Women

The Women, Infants, and Children (WIC) Nutrition Program provides low-income women (prenatal and postpartum), infants, and children with nutrition education, breastfeeding support, healthy foods, and referrals. There is strong evidence that WIC services effectively improve birth outcomes and the health of infants, particularly for mothers with inadequate prenatal care [16]. Based on recommendations from the Institute of Medicine [17], the WIC food package for women focuses on foods rich in folic acid, such as fortified cereals, whole grains, fruits, and vegetables. Postpartum women also receive education at WIC on the importance of taking a folic acid supplement prior to their next pregnancy. WIC is able to provide these services to some of the women at greatest risk of not taking folic acid [18].

Currently, postpartum women who are breastfeeding receive WIC education and foods up to one year after delivery. Nonbreastfeeding postpartum women, however, only receive WIC benefits until six months after delivery. This means that out of 1.3 million postpartum women on the WIC program, approximately half of them do not continue to receive nutrition counseling and healthy WIC foods beyond six months [19]. Extending all women's eligibility to one year or longer postpartum would provide (1) additional time for folic acid education, (2) access to folate-rich foods, and (3) referrals to healthcare professionals for folic acid supplement prescription. Research suggests that health interventions during the postpartum period can greatly promote behaviors such as use of a multivitamin during childbearing age [20]. Extending WIC eligibility for up to one year for all postpartum women would improve birth outcomes and reduce healthcare costs in the future.

### **CONCLUSION**

Despite fortification of enriched grain products and research supporting early folic acid supplementation, many women are still not consuming the recommended amount of folic acid during their childbearing years. Government support is needed for implementation of three key solutions to this problem: the expansion of Medicaid coverage for folic acid supplements without preauthorization, improved technology-based folic acid supplement education, and the one-year extension of WIC for postpartum women. These opportunities have the potential to decrease neural tube defects in the United States, as well as the accompanying emotional devastation and overwhelming healthcare costs associated with these conditions.

#### **AUTHORS AND ACKNOWLEDGEMENTS**

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