

## Folic Acid and Birth Defects Prevention: A Public Health Success Story

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Not very many years ago, prevention of birth defects was rarely given serious consideration as an important public health strategy for reducing infant mortality and improving birth outcomes. Some common misconceptions about birth defects—that they are rare events which account for relatively few infant deaths, and that they are essentially unpreventable—probably contributed to the fact that birth defects were largely overlooked as a focus of most infant mortality reduction efforts. Yet, contrary to the perception of many people, birth defects (or congenital malformations, as they are sometimes described) are not that rare. Approximately 3% of all infants are born with serious birth defects. In North Carolina, that translates to about 3,000-3,500 babies affected each year—a number that is 50% greater than the number of babies who are born with very low-birth weight. Birth defects are listed as the underlying cause of death in about one in every five infant deaths in North Carolina, and approximately 30% of all infants who die in the first year of life have one or more birth defects diagnosed. Moreover, many types of birth defects are largely or entirely preventable. Some examples include fetal alcohol syndrome, retinoic acid embryopathy, congenital rubella syndrome, and folic acid preventable birth defects such as anencephaly and spina bifida. While it is true that the etiology of the majority of birth defects is currently unknown, the same is also true for most preterm births, yet the latter still has been a chief focus of infant mortality reduction efforts for decades.

Beginning in the early 1990s, a series of landmark events began to set the stage for a significant change in the perception of birth defects as an issue deserving of public health attention. The first of these was the completion of the randomized controlled trial conducted by the Medical Research Council in the United

Kingdom which, building upon previous observational studies, demonstrated that preconceptional intake of the B-vitamin folic acid could prevent up to 70% of spina bifida and anencephaly, the two most common types of neural tube defects (NTDs).<sup>1</sup> In September 1992, the US Public Health Service published the recommendation that “All women of childbearing age in the United States who are capable of becoming pregnant should consume 0.4 mg of folic acid per day for the purpose of reducing their risk of having a pregnancy affected with spina bifida or other neural tube defects.”<sup>2</sup> In 1996 the Food and Drug Administration promulgated a rule requiring all enriched grain products to be fortified with folic acid, effective January, 1998. Subsequently, the national Institute of Medicine reaffirmed the US Public Health Service recommendation and added that women of childbearing years should take 0.4 mg of *synthetic* folic acid daily.

In North Carolina during this time, a concerted effort took

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root to reduce the prevalence of neural tube defects by promoting awareness and consumption of folic acid among women of childbearing age. In 1994, the NC Neural Tube Defect Task Force, later renamed the NC Folic Acid Council, was created. North Carolina was among the first states in the United States to establish such a council, and the group has achieved national recognition for the leadership role it has taken to promote the benefits and consumption of folic acid. Recognizing the need for better surveillance data to help design, target, and evaluate folic acid interventions, the Council worked with the NC General Assembly to establish the NC Birth Defects

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Monitoring Program (BDMP) in 1995. The purpose of the BDMP is to collect, analyze, and disseminate critical information needed for the prevention and treatment of birth defects in North Carolina.

Data from the BDMP indicated that the neural tube defect rate in North Carolina was approximately twice the national rate, and that the rate in the western part of the state was nearly three times that of the United States. Thus, the initial focus of the state's folic acid awareness efforts concentrated in the western region, in partnership with the Fullerton Genetics Center and other key healthcare providers in the region. The results of these efforts were impressive. Between 1995 and 2002, the prevalence of NTDs in the western region has decreased by about 75%—or approximately twice the decline seen compared to the state as a whole which, concurrently, had also reaped significant benefits from an array of local, state, and national folic acid initiatives. These initiatives include the fortification program and numerous public awareness campaigns both within and outside the state. The success of these efforts are evident by recent data from the BDMP. Statewide in the year 2002 alone, there were an estimated 80-90 fewer pregnancies affected by NTDs compared to the number that would have been expected had the rates remained the same as in 1995 (prior to folic acid interventions). More than one-half of these pregnancies probably would have ended in medical termination or fetal/infant death, while the remaining infants would have been born with significant disability and other serious health problems.

The BDMP provides the foundation for the Folic Acid Campaign. The program's surveillance data inform the Campaign regarding populations of greatest need, help the Campaign evaluate its effectiveness, and aid in strategic planning. It is also useful to combine these data with information from the Pregnancy Risk Assessment Monitoring System (PRAMS) and the Behavioral Risk Factor Surveillance System (BRFSS) in order to track trends in folic acid knowledge and consumption. With longstanding support from the March of Dimes, the NC Folic Acid Campaign conducts community and healthcare provider education, vitamin distribution, and media campaigns in its efforts to educate North Carolinians about preventing neural tube defects by taking folic acid daily.

The Campaign has succeeded in raising awareness about the benefits of folic acid. Data from NC PRAMS show that in 2001, 86% of women who gave birth that year had heard or read about folic acid (up from 74% in 1998); however, the fact that still only 27% of women reported taking it every day before becoming pregnant indicates that much work remains

to be done before all folic acid preventable birth defects are eliminated. The major challenge now lies in reaching those sociodemographic populations in which the prevalence of NTDs has not declined substantially, and in which multivitamin use remains low. For example, a recent analysis by the BDMP found that the prevalence of spina bifida had decreased very little among women who were less than 25 years of age, who had less than a high school education, and who were on Medicaid compared to their counterparts who were older, better educated, and not receiving Medicaid.<sup>3</sup> Efforts to refocus the Campaign on these populations are already underway.

There is still much work to be done by the Folic Acid Campaign and by healthcare providers. Of the women who know that folic acid prevents birth defects, but do not take vitamins, 89% say they would take vitamins containing folic acid if their healthcare providers recommended they do so.<sup>4</sup> This is a tremendous opportunity for healthcare providers to create public health change by causing a change in the behavior of patients. Every woman who is capable of becoming pregnant should be encouraged by her physician to take 0.4 mg (400 mcg) of folic acid in the form of a multivitamin every day, in addition to eating a well-balanced, healthy diet. Because the development of the neural tube occurs within the first few weeks of pregnancy (often before a woman even knows she is pregnant), it is essential to stress that folic acid must be taken *every day before pregnancy* and continued through at least the first trimester.

In their article elsewhere in this issue of the *Journal*, DeClerque et al.<sup>5</sup> highlight the need for infant mortality prevention efforts to place a greater emphasis on improving the health of women before they become pregnant. Those who have been involved with birth defects prevention have long recognized the fact that the preconceptional period is the only viable window for effective primary prevention, because most major structural congenital malformations occur very early in pregnancy. Although we do not yet fully understand the mechanisms leading to early preterm birth and we do not know when the optimal window for prevention is, it is only reasonable to assume that, in general, the healthier a woman is before pregnancy, the better her chances are of having a full-term, healthy infant. In their paper DeClerque and colleagues call for a "paradigm shift" toward focusing on improving preconceptional health—and more generally *women's health*—as a strategy for combating infant mortality. That recommendation, which has the potential for reducing infant morbidity and mortality related to both birth defects and low-birth weight, is a welcome one indeed. **NCMJ**

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