

## Introduction: Birth Defect Surveillance in the United States

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This issue of *Teratology* is the third edition devoted exclusively to reporting birth defects surveillance data from the United States; the first was published in 1993 (CDC, '93) and the second in 1997 (NBDPN, '97). This issue contains descriptions of birth defect surveillance activities in all states and presentations of surveillance data from 29 of those programs. As noted in the 1993 surveillance issue of *Teratology*, public health surveillance involves the collection and assessment of data on the occurrence of disease in human populations. The purpose of doing this is to learn where, when, and among whom disease is occurring. This knowledge is essential to understanding causes of birth defects and to ensuring the efficient operation and evaluation of prevention programs.

The number of programs contributing data to this issue of *Teratology* signals the growth and increasing maturity of birth defect surveillance in the United States and the degree to which birth defects prevention and epidemiologic assessment activities are being integrated into state and local public health departments. In the past, much of the motivation for establishing birth defect surveillance systems was public concern about the possible role of environmental factors in the occurrence of birth defects. Data from surveillance systems have been used to establish registries of case and control infants that are used in epidemiologic studies addressing such concerns. However, as the number of surveillance programs has grown, the uses of the data have expanded and diversified. In this issue, Walker discusses the integration of birth defect surveillance in maternal and child health

programs at the state level, and Kirby describes the uses of surveillance data in the provision of clinical genetic services. Khoury presents the relationship between surveillance data and the potential use of emerging human genetic information for prevention. Kirby et al. describe data on rates of several kinds of birth defects among children born to Hispanic mothers in seven states.

The increase in birth defect surveillance and prevention activities is due in large measure to the continuing advocacy on behalf of pregnant women and babies by the March of Dimes and to the interest of numerous members of the U.S. House and Senate. In the introduction to the 1997 NBDPN report of surveillance data, I described proposed legislation before the U.S. Congress. At that time, none of those legislative proposals had been passed. However, on April 21, 1998, an authorization bill, the *Birth Defects Prevention Act of 1998*, was signed into law. Authorization bills provide the Executive Branch of the U.S. Government with the authority to carry out certain functions, whereas appropriations bills provide agencies with Government funds for specific activities. In July 1999, another authorization bill, *Folic Acid Promotion and Birth Defects Prevention Act of 1999*, was introduced in the Senate and in the House proposing that the Public Health Service Act be amended to provide for a national folic acid education program to prevent birth defects.

In 1994, Congress directed CDC to help state health departments improve their surveillance capabilities and appropriated funds for that purpose. From those funds, CDC awarded small grants to 12 state health de-

partments that were used in a variety of ways to bolster state birth defects surveillance and prevention activities. In 1999, CDC was given appropriations that made it possible to provide larger grants to 18 state health departments to establish or improve their birth defect surveillance systems. A congressional mandate also requires CDC to help state health departments develop a clearinghouse or network of birth defect surveillance programs in the United States. In response to this mandate, CDC helped establish the National Birth Defects Prevention Network (NBDPN), in 1996. In January 1999, the NBDPN held a meeting that was attended by representatives from the 50 states, the District of Columbia, and Puerto Rico.

In 1992, the Public Health Service (PHS) recommended that all women capable of becoming pregnant should consume 400  $\mu\text{g}$  of folic acid for the purpose of preventing spina bifida and other neural tube defects (NTDs) (CDC, '92). In 1998, the Standing Committee on the Scientific Evaluation of Dietary Reference Intakes of the Institute of Medicine (IOM) released a report regarding dietary reference intakes for folates and other B-vitamins (IOM, '99) that affirmed and clarified the PHS recommendation. The Committee recommended that "...women capable of becoming pregnant take 400  $\mu\text{g}$  of synthetic folic acid daily, from fortified foods or supplements or a combination of the two, in addition to consuming food folate from a varied diet." The IOM report emphasized the synthetic form of the vitamin because the research on which the recommendation is based used synthetic folic acid, and because synthetic folic acid is more readily absorbed than the folate compounds that occur in natural foodstuffs.

In 1996, the Food and Drug Administration (FDA) mandated that by January 1998 all "enriched" cereal grain products (such as bread and pastas made with "enriched" flour) should contain 100  $\mu\text{g}$  of synthetic folic acid per 100

g flour. The FDA estimated that this will add about 140  $\mu\text{g}$  of folic acid to the diet of the average woman, only about one-fourth of the recommended daily consumption. Therefore, until more women begin to take dietary supplements (CDC, '99) or substantially increase their consumption of foods made with folic acid-fortified flour, most women in the United States will not meet the PHS- and IOM-recommended level of folic acid intake. In recognition of this need, the National Council on Folic Acid, which comprises more than 40 organizations, has been formed. The member organizations of the Council are conducting activities directed at increasing the consumption of folic acid by reproductive-age women. The Council held a campaign "kick-off" meeting in January 1999. Representatives of many state birth defect surveillance programs attended the meeting, and the 1999 meeting of the National Birth Defects Prevention Network was held just before the Council meeting.

Despite the finding that most women do not meet the PHS and IOM recommendations for the daily consumption of 400  $\mu\text{g}$  of folic acid, the results of two recent studies suggest that fortification has resulted in significant increases in average serum folate levels, at least in some segments of the U.S. population (Jacques et al., '99; Lawrence et al., '99).

Reducing the number of cases of neural tube defects that occur in the United States each year was the motivating factor for fortification of the food supply. Now it remains to document whatever effect the important public health action of fortification has had. At one time, NTD surveillance was easy, and surveillance findings were considered relatively complete, even when based on data from vital records. Today however, perhaps as many as one-third of all NTDs are detected in utero and the pregnancies terminated (Cragan et al., '95). Ascertaining NTD cases that have been diagnosed prenatally thus requires the devel-

opment of information sources that have not been traditionally used by surveillance programs. This fact will complicate the assessment of progress being made in the prevention of NTDs through increased folic acid consumption.

In 1997, on behalf of the National Birth Defects Prevention Network, Miller and Kirby undertook a survey of state health agencies and birth defects surveillance programs to determine how NTD surveillance data were being collected and applied to activities aimed at the prevention of these defects. Their results, presented here, show that only 25 states used a statewide surveillance program to monitor the occurrence of NTDs. In addition, they found that “many” states did not use their data in prevention or intervention programs. The 1999 CDC grants to state health departments may help to improve this situation. All awardees are required to use at least a portion of the awarded funds to establish NTD surveillance and to promote the prevention of these serious defects through increased consumption of folic acid by reproductive age women.

The urgent need to evaluate the impact of folic acid fortification on the occurrence of NTDs is a significant challenge for the National Birth Defects Prevention Network, but

as this issue of Teratology demonstrates, it is a challenge that the NBDPN has made substantial progress toward meeting.

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