

# *Neural Tube Defects: The Impact of Prenatal Diagnosis on Rates*

**A** important function of a birth defects registry is tracking rates and trends over time. Traditionally, epidemiologists look at rates among live births and fetal deaths. Pregnancy terminations for fetal birth defects—becoming more widespread with the increasing use of prenatal diagnosis—are not counted in these birth statistics. How does this affect risk estimates?

The California Birth Defects Monitoring Program examined population-based data on neural tube defects for the years 1989-1991. As part of an interview study of this condition, we identified all cases of spina bifida, anencephaly and other neural tube defects among pregnancy terminations, live births, and fetal deaths.

## **40% ELECTIVE TERMINATIONS**

We identified 664 pregnancies/births with neural tube defects from a population with over 700,000 births; most cases had spina bifida or anencephaly.

- Counting all pregnancy outcomes, neural tube defects were seen in 0.94 per 1000 births, about 550 cases each year in California.
- Among liveborn or stillborn infants, the rate of neural tube defects was 0.56 per 1000.

- 40% of neural tube defect cases were electively terminated, 50% were liveborn, and 10% were stillborn after 20 weeks gestation.
- The rate of anencephaly among live births and fetal deaths was 0.19 per 1000—48% of the rate including all pregnancy outcomes, 0.39 per 1000.
- The rate of spina bifida among live births and fetal deaths was 0.35 per 1000—70% of the rate including all pregnancy outcomes, 0.50 per 1000.

### **AFP SCREENING FOR NEURAL TUBE DEFECTS**

- A blood test on the mother—AFP screening—can identify pregnancies at high risk for neural tube defects.
- Further testing with ultrasound and/or amniocentesis determines if the fetus is affected.
- Since 1986, California law requires all pregnant women be offered AFP screening. The test fee includes any recommended follow-up procedures, including genetic counseling.
- AFP screening is done at 15-20 weeks gestation. Testing and follow-up is completely voluntary.

## MOTHER'S CHARACTERISTICS BY PREGNANCY OUTCOME

	Elective Termination	Live Birth/ Fetal Death
White	51%	33%
US-born Latina	16%	12%
Foreign-born Latina	22%	45%
≥ 25 years old	72%	48%
High school graduate	77%	51%
Employed	76%	59%
Household income ≥\$30,000	50%	25%
Prenatal care ≤4 months	93%	78%
Had AFP screening	70%	28%
Used vitamins/folic acid	78%	47%

### CHARACTERISTICS AMONG TERMINATIONS

Pregnancies with anencephaly were more likely to be terminated than pregnancies with spina bifida. 54% of electively terminated pregnancies were 20 weeks gestation or beyond.

Women who electively terminated pregnancies had different demographic characteristics than those who delivered liveborn or stillborn infants. They were more likely to be white, over age 24, have graduated from high school, be employed, and have a household income above \$30,000. Almost all had sought prenatal care during the first 4 months of pregnancy, and about two-thirds had AFP screening.

### IMPACT ON SCIENTIFIC STUDIES

- When documenting trends or calculating risks, excluding electively terminated cases seriously underestimates the true prevalence of neural tube defects.

- In studies of risk factors, selecting participants based on pregnancy outcome could skew results. For instance, many studies of neural tube defects look at women's use of vitamins containing folic acid, a protective factor. In this study, 78% of those who terminated pregnancies used vitamins around the time of conception compared to only 47% among those who gave birth.

### DATA SOURCES

All cases were identified through ongoing surveillance by the California Birth Defects Monitoring Program registry, an actively ascertained, population-based database of information on children with birth defects.

- **Pregnancies included:** 708,129 pregnancies in 55 California counties, with delivery or due dates between June 1989 through May 1991.
- **NTD cases:** 279 anencephaly, 352 spina bifida, 26 other types of neural tube defects.
- **Diagnostic information:** Abstracted from hospital medical records, including surgical and autopsy reports.
- **Demographic and other information:** From in-home interviews with 538 case mothers.

*REFERENCE: Velie EM, Shaw GM. Impact of prenatal diagnosis and elective termination on prevalence and risk estimates of neural tube defects in California, 1989-1991. American Journal of Epidemiology 1996;*

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