

Birth Defects

Overview

National estimates suggest that 3-5% of children are born with a birth defect of some kind. The March of Dimes estimates that 1,752 babies are born with a birth defect annually in Oregon (March of Dimes *Perinatal Profiles*, 2000). In 2000, 25% of infant deaths (first year of life) and 32.7% of neonatal deaths (first month of life) were due to congenital anomalies, including chromosomal disorders. The impact of birth defects is far-reaching and includes physical, emotional, and financial effects on families and society.

Services

(See [Children with Special Health Care Needs Summary](#).)

Data and Surveillance

Oregon does not have a birth defects registry. In 1992/93 the Department of Human Services (DHS) considered the possibility of starting an active surveillance program; however, during a meeting of DHS, The Children's Development and Rehabilitation Center (CDRC), and several other constituents, consensus was reached not to develop a system at that time—though such a system was desirable, neither state nor federal funds were readily available for this purpose, and other issues were of higher priority. Discussions regarding the need and feasibility of developing a birth defects surveillance system are ongoing.

Some information about some birth defects (congenital anomalies) are collected on birth certificates. This information includes major structural anomalies and chromosomal disorders such as Down syndrome. The quality and accuracy of this information depends on recognition of anomalies or conditions within the first few hours of life, medical record documentation by the infant's health care provider, and extraction of this information by birth certificate clerks.

Teratogen Information Services

Approximately 10% of birth defects are related to known maternal illnesses, drugs, chemicals, or other teratogenic exposures (*CARE Northwest statistics*). Oregon does not have a state-specific teratogen information service; however, these services are available through CARE Northwest, based at the University of Washington in Seattle. CARE Northwest is a 900 number telephone service that provides up-to-date, accurate information about pregnancy and lactation exposures to environmental agents such as drugs, chemicals, viruses, or pollutants. The service offers fee-for-service clinic counseling for individuals who have high risk exposures or anxiety concerning an exposure. Fact sheets about

various conditions are also available on line at the CARE Northwest website (depts.washington.edu/chdd/ucedd/CO/co_CareNW.html).

In Oregon, the Environmental Health Program within the DHS Office of Disease Prevention and Epidemiology routinely answers individual inquiries from the public about teratogenic substances. It also develops and issues advisories on substances that could be hazardous to unborn fetuses, such as mercury in Oregon river fish.

Birth Defects Prevention & Education

Folic Acid

Birth defects of the brain and spinal cord, called neural tube defects (spina bifida and anencephaly) affect approximately 4000 pregnancies a year in the US. Studies have suggested that women who take multivitamins with 400 micrograms of folic acid before and during the first few weeks of pregnancy can significantly reduce their risk of having a child with a neural tube defect and possibly other birth defects as well. The Pregnancy Risk Assessment and Monitoring System and the Behavioral Risk Factor Surveillance System are the primary sources of information about Oregonians' use of folic acid.

In 1999, 79% of postpartum women surveyed in the Pregnancy Risk Assessment and Monitoring System survey indicated that they had heard that taking folic acid could help prevent some birth defects. However, only 30% of the women reported they were taking folic acid in the month prior to becoming pregnant, a critical time for prevention of neural tube defects.

Folic acid educational activities include:

- The March of Dimes (MOD) has completed a multi-year Folic Acid Campaign, designed to reach women through community action, health professional education, and mass media. This national effort has been carried out in Oregon by the Greater Oregon chapter of MOD along with DHS/Health Services (DHS/HS). A MOD informational brochure about preventing birth defects is given to individuals applying for a marriage license.
- In 2002 DHS/HS received a grant for \$15,000 from the March of Dimes for folic acid community and professional education activities.
- The Oregon Women, Infants, and Children (WIC) program identified inadequate folic acid intake as a risk factor for postpartum women (both breastfeeding women and non-breast feeding women). All postpartum women applying to the program are asked, through a health questionnaire, if they have taken any folic acid supplementation or eaten 100% fortified cereal.
- The Oregon WIC program developed a folic acid counseling protocol and is planning a variety of client educational activities, including a one-page

- brochure on folic acid as well as indicating which cereals on their shopping brochure are 100% folic acid fortified.
- The Marion County Health Department is piloting an “every women, every encounter” approach to folic acid education. Before a health care provider sees female patients for the concern that brought them to the clinic, a nurse will give them information about folic acid.
 - The Umatilla County Health Department is distributing multivitamins with folic acid in their family planning clinics.

Fetal Alcohol Syndrome

Fetal alcohol syndrome (FAS) is a complex of birth defects including cardiac, cranial, facial, and neural abnormalities, and physical and mental growth retardation that results from excess maternal alcohol consumption during pregnancy. It is the most common preventable cause of mental retardation. The incidence is estimated to be 1/1000. The diagnosis is based on clinical findings including facial features, family history and maternal alcohol history; however, the diagnosis is often difficult to establish since there are no confirmatory laboratory tests. In 2000, nine newborns out of 45,786 Oregon births were identified on birth certificates as being affected by fetal alcohol (incidence 1:5000); however, many such children may not be recognized until much later.

There are currently no systematic fetal alcohol syndrome prevention or monitoring programs in Oregon, though county clerks are required by law to provide information about fetal alcohol syndrome when they give out marriage licenses. In 2001 the Office of Drug Alcohol and Drug Abuse Programs received a budget note from the legislature requiring that the Office work with the Health Division, the Office of Mental Health Services, and the Office of Services to Children and Families to develop a plan to address Fetal Alcohol Syndrome. To ensure swift access to services for high-risk women, the plan should include identifying data collection methodologies, training of health and social service providers, and improving referral systems. A committee of representatives from these agencies has been working over the past year to develop the FAS plan. In addition to DHS activities, the Portland Area Indian Health Board is involved in assessing and planning for fetal alcohol syndrome prevention activities. Another organization, Fetal Alcohol Syndrome Consultation, Education and Training Services, Inc. (FASCETS), a private non-profit organization based in Portland, provides information, training, direct services, referrals, partnership development, consultation, program augmentation, and development on FAS-related issues. They serve individuals with FAS or alcohol-related neurodevelopmental disorder, parents, health care professionals, educators, social service providers, etc. They maintain a helpful website (www.fascets.org).