

Description:

Accurate birth defect tracking and evaluation are critical to promote healthy pregnancies and support affected families. The Utah Birth Defect Network (UBDN) is a statewide public health program that tracks and assesses birth defects in Utah. Birth defects critically threaten the health and survival of Utah children. In Utah, birth defects are the leading cause of infant deaths and a major cause of pediatric hospitalizations. Preventing some birth defects is now possible. However, the cause of 80% of all birth defects currently is unknown. The UBDN has the opportunity to identify causes and implement prevention activities for children in Utah.

Birth defects are common, deadly, and costly. **In Utah:**

- 1 in 30 babies are born with birth defects -- ~ 1,400 are born each year
- The rate of cleft lip and cleft palate is the highest in the US (1 in 450 babies)
- Severe defects of the brain and spine (spina bifida and anencephaly) are increasing.
- Gastroschisis (an abnormality of the abdominal wall) is increasing.
 - As a result of the UBDN's federal funds, we were able to identify sexually transmitted infections (Chlamydia) and urinary tract infections as risk factors for gastroschisis. In Utah, sexually transmitted infections (Chlamydia) are increasing.
- Hypospadias is increasing among male infants
- Insulin dependent diabetes is the most frequent and preventable cause of birth defects in Utah.

During the past year:

- The UBDN is currently investigating a reported cluster, made by a concerned parent, of congenital heart defects in Utah valley where several babies have been born with similar heart defects within a neighborhood.
- The UBDN provides information over the telephone to concerned parents regarding their child's birth defect and referrals

Benefits of Birth Defect Surveillance, Education and Prevention Activities:

The UBDN is a key component of Utah's public health system and provides essential services to the people and policy makers of Utah. This investment provides cost effective benefits which include:

- Accurate, timely data: UBDN is Utah's only source of accurate birth defect data.
- Prevention opportunities: The State pays twice for many children with birth defects (i.e., Medicaid and Early Intervention)
- Substantial savings: Over 50% of babies with birth defects receive Medicaid assistance. Reducing babies born with birth defects by improving preconception healthy behaviors will be a cost savings to the state.
- Ongoing education and outreach: These activities support Utah's families in promoting healthy pregnancies, healthy babies, and optimal health for affected children.

UBDN benefits Utah's families and communities by using these data to provide essential services, including:

- A safety net that identifies and responds to epidemics of birth defects
- A system to detect preventable causes of birth defects;
- A resource for families, to promote optimal health of affected children;
- A service providing timely, accurate data for policy development and evaluation.

Program Impact:

Without UBDN's accurate data and experienced infrastructure, the leading cause of infant deaths in Utah will be left unchecked, with no reliable way to evaluate interventions and prevention, and monitor for epidemics.

For additional information, please contact:

George Delavan, M.D., Division Director
Division of Community & Family Health Services,
Utah Department of Health