



PREVENTION OPPORTUNITIES UNDER THE BIG SKY

Early Identification of Cleft Lip and Palate in Montana

Cleft lip with or without cleft palate is the second most common birth defect reported in the US.¹ Early intervention is important to address the effects of the cleft on eating and speech, as well as any other related issues that could affect a child's health and development, such as weight gain, ear infections, hearing loss, and dental issues. Treatment for children born with a cleft needs to begin at birth and continue throughout childhood, adolescence, and occasionally into adulthood.

Birth certificates are often the earliest source of data on cleft diagnoses and may be used to refer children to specialty services. With timely referral, infants and parents can receive assistance with feeding and information about surgical correction very soon after birth. An assessment of how completely cleft is reported on birth certificates can identify key gaps in the identification and referral process. In Montana, the Children's Special Health Services (CSHS) clinic database, CHRIS, includes diagnoses for all children referred to the CSHS Program for cleft/craniofacial specialty services. Cleft data from birth certificates and the clinic database were compared to determine how many children born with clefts in Montana and referred to the CSHS clinics did not have the condition reported at the time of birth.

Cleft lip and/or palate A cleft is a split or separation in the oral (mouth) structures. Cleft lip and/or palate occur when portions of the lip, nose, or hard or soft palates do not completely fuse together during fetal development. A child can be born with a cleft of the upper lip, a cleft of the palate (roof of the mouth), or a cleft of both.

Cleft lip may involve only part of the upper lip (incomplete) or the upper lip into the nose (complete). A lip cleft can be unilateral (on one side of the lip) or bilateral (on both sides of the lip).

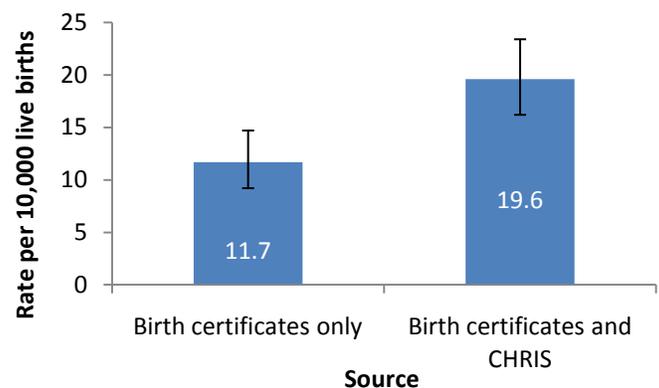
Cleft palate can also be unilateral or bilateral and may include only the soft or hard palate, or both. Submucous clefts are the most difficult to identify, because the mucous membrane on the palate is intact, but there is a midline deficiency or lack of muscular tissue and incorrect positioning of the muscles of the soft palate. Submucous clefts are often associated with a bifid or cleft uvula.

Both cleft lip and palate occur during the first trimester of pregnancy. The specific causes of cleft are not known, although genetic risk likely exists, and smoking during pregnancy increases the risk of having an infant with a cleft.² Cleft is also often associated with syndromes and other conditions. Folic acid may help in preventing clefts.³

Prevalence of cleft in Montana In 2004-2008, 70 infants had a cleft lip and/or palate reported on the birth certificate, a prevalence of 11.7 per 10,000 live births (95% confidence interval 9.2-14.7). The CHRIS database identified an additional 47 children born in

Montana in 2004-2008 diagnosed with a cleft. The additional 47 children increased the prevalence of cleft in Montana to 19.6 per 10,000 live births (95% confidence interval 16.2-23.4) in 2004-2008. (Figure)

Figure. Prevalence of cleft in persons born in Montana, 2004-2008, by source of ascertainment



I - Indicates 95% confidence interval.

Source: Montana Office of Vital Statistics and Child Health Referral Information System

Clefts not reported on birth certificates At least forty percent of clefts in infants born in Montana in 2004-2008 were not reported on the birth certificate.

Information on the type of cleft was available for 111 of the 117 children diagnosed with a cleft. Children with a cleft palate with no lip involvement were less likely to have the condition reported on the birth certificate than were children with a cleft lip or lip and palate (X^2 $p < 0.05$, Table), possibly because clefts that involve the lip

are more easily identified without a thorough examination.

Birth certificate data are often the source for reporting the prevalence of conditions like cleft and identifying the magnitude of cleft as a health concern among Montana children. Underreporting on birth records can result in an impression that the rate of cleft in Montana is lower than it actually is. More important, underreporting of cleft on birth certificates may result in delayed referral to intervention services.

Cleft resources Interdisciplinary cleft clinics are held throughout the year at sites around Montana. Cleft clinics are staffed by a cleft/craniofacial team that includes a craniofacial specialist/plastic surgeon, pediatrician, audiologist, speech/language pathologist, dentist, orthodontist, otolaryngologist (ENT), social worker, psychologist, nutritionist, and geneticist.

The Montana Cleft/Craniofacial Team provides evaluations, anticipatory guidance, education for families and their child, recommendations for care, coordination of follow-up with a child's primary care provider as well as other specialists, and assistance with health care coverage, payment for services, and other resources.

Table. Cases of cleft in persons born in Montana, 2004-2008, by cleft type and source of ascertainment

Type of cleft	Ascertainment source			TOTAL
	Birth certificates and CHRIS	CHRIS only	Birth certificate only	
Cleft lip and palate	15 (31%)	32 (67%)	1 (2%)	48
Cleft lip only	9 (36%)	12 (48%)	4 (16%)	25
Cleft palate only	23 (61%)	15 (39%)	0	38

Recommendations to clinicians:

- Conduct an assessment for cleft directly after birth and report all cases of cleft on the birth certificate.
- Refer children with cleft/craniofacial conditions to the cleft/craniofacial clinic in your region. Clinic locations and contact information can be found on the CSHS website: <http://www.dphhs.mt.gov/PHSD/family-health/cshs/cshs-clinic-contacts.shtml>, or by contacting MaryLynn Donnelly, Public Health Nurse Consultant with CSHS, at 406-444-3620.
- Assess the family's need for support and other resources.
- Counsel women to stop smoking prior to pregnancy.
- Recommend that women take a daily multi-vitamin containing at least 400 micrograms of folic acid prior to becoming pregnant, and 600-1000 micrograms during pregnancy.
- Recommend genetic counseling for families with a history of cleft.
- Collaborate with the interdisciplinary teams on care for children with cleft/craniofacial conditions.

For more information about cleft lip and palate in Montana and Children's Special Health Services specialty clinics, contact MaryLynn Donnelly, Public Health Nurse Consultant with the Children's Special Health Services program, at (406) 444-3620 or mddonnelly@mt.gov.

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