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Birth Defects Data from Population-based Birth Defects Surveillance Programs in the United States, 2007 to 2011: Highlighting Orofacial Clefts

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Keywords

orofacial clefts; birth defects; population-based surveillance

Introduction

The National Birth Defects Prevention Network (NBDPN) published the first Congenital Malformations Surveillance Report in 1997 and has annually released a report since 2000 that contains state-specific population-based data on major birth defects and a directory describing data collection information for population-based birth defects surveillance programs in the United States. The birth defects in these reports have included conditions

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affecting major organs of the central nervous, eye, ear, cardiovascular, orofacial, gastrointestinal, genitourinary, and musculoskeletal systems, as well as other disorders, including trisomies and amniotic band sequence.

In 2014, the NBDPN released an updated list of major birth defects as part of its national standards development for birth defects surveillance. The criteria used to guide deliberations for inclusion on the reportable list were: (1) public health importance; (2) accuracy of diagnosis; (3) amenable to prevention/intervention; (4) state of knowledge; (5) structural malformations, diagnosed within the first year of life; and (6) ability to separate into syndromic/nonsyndromic. For example, the NBDPN list now includes all 12 critical congenital heart defects (CCHDs) that are primary and secondary targets of pulse oximetry screening as a result of the addition of CCHD to the U.S. Recommended Universal Screening Panel for newborns (Mahle et al., 2012). Other noncardiac conditions that were added include clubfoot, cloacal exstrophy, craniosynostosis, deletion 22q11.2, holoprosencephaly, small intestinal atresia/stenosis, and Turner syndrome. These additions were balanced with the removal of several conditions, including: amniotic bands, aniridia, congenital hip dislocation, epispadias, fetus or newborn affected by maternal alcohol use, Hirschsprung disease (congenital megacolon), hydrocephalus, microcephalus, patent ductus arteriosus, and pyloric stenosis. Additional modifications to the list resulted in the regrouping of some conditions. Upper and lower limb deficiencies were collapsed into all limb deficiencies, while cleft lip with or without cleft palate was separated into cleft lip alone and cleft lip with cleft palate. Finally, obstructive genitourinary defect was limited to just the reporting of congenital posterior urethral valves. Table 1 presents the new reported list of birth defects and their diagnostic codes (International Classification of Diseases, 9th Revision, Clinical Modification [ICD-9-CM]; and Centers for Disease Control and Prevention/British Pediatric Association Classification of Diseases [CDC/BPA]).

The current report includes state-specific data from 39 population-based birth defects surveillance programs for the updated list of 47 major birth defects, and an accompanying directory describes program data collection status and contacts for state birth defects surveillance activities. In addition, the report highlights orofacial clefts (OFCs) from 29 state programs.

State-specific Data Collection and Presentation of 47 major birth defects

DATA COLLECTION

The NBDPN Data Committee, in collaboration with CDC, issued a call for data to population-based birth defects surveillance programs in April 2014. State programs were provided with a data dictionary and data table creation tools in Excel and SAS. CDC performed data quality checks, and state programs validated their data and approved final data table presentation.

Participating birth defects surveillance programs submitted case counts of the reportable birth defects shown in Table 1 and live births occurring from January 1, 2007 through December 31, 2011. These cases were stratified by U.S. Census maternal racial/ethnic groups: non-Hispanic white, non-Hispanic black, Hispanic, non-Hispanic Asian/Pacific

Islander, non-Hispanic American Indian/Alaska Native, and other/unknown. Additionally, trisomy conditions (trisomy 21 [Down syndrome], trisomy 13, and trisomy 18) were stratified by six maternal age categories: less than 20 years, 20 to 24 years, 25 to 29 years, 30 to 34 years, 35 to 39 years, and 40+ years.

DATA PRESENTATION

State-specific data from 39 population-based birth defects surveillance programs for 2007 to 2011 are included in the supplemental materials. The data are presented in two tables for each state. The first table shows defect counts and prevalence per 10,000 live births by maternal racial/ethnic categories, and the second table presents counts and prevalence for trisomies by two maternal age categories (less than 35 years, 35+ years). The prevalence is calculated by dividing the number of birth defect cases for any pregnancy outcome by the total number of live births for the reported years and then multiplying by 10,000 (Mason et al., 2005). The denominator used to calculate the prevalence for all birth defects is total live births except for hypospadias, which is calculated using total male live births.

Although the NBDPN provided a data dictionary and attempted to obtain the data in a uniform manner, variability can be expected in the reported birth defects data by state programs, given differences in coding systems used for case inclusion, case-finding methodology, and available data sources. State-specific notes and clarification about the data, such as methodological changes and probable/possible diagnoses, are included in the data tables. Additional information about each state program data collection methodology is available in the accompanying program directory.

Highlighting Orofacial Clefts

In addition to submitting data for the 47 NBDPN reportable birth defects, 29 state programs submitted supplemental data for this feature on orofacial clefts (OFCs). OFC are a phenotypically and etiologically diverse group of malformations that include cleft lip alone, cleft palate alone, and cleft lip with cleft palate, as well as several atypical cleft variations (Watkins et al., 2014). Orofacial clefts are among the most common major structural birth defects. In the United States, approximately 1 in 940 infants are born with cleft lip with or without cleft palate, and approximately 1 in 1574 infants are born with cleft palate (Parker et al., 2010).

Cleft lip alone and cleft lip with cleft palate both involve a bilateral, unilateral, or central defect of the upper lip that is visible in the newborn and often can be detected by prenatal ultrasound. In cleft lip alone, the defect can extend to the nasal floor, while in cleft lip with cleft palate, there also is a malformation of the upper gums (maxillary alveoli) or roof of the mouth (palate) that is often continuous with the separation of the lip. Cleft palate alone involves a hole or separation in the hard palate, soft palate, or the uvula (dangling structure at the rear of the soft palate), without a cleft lip.

Like other types of birth defects, OFCs are often classified by the presence or absence of other major malformations. *Nonisolated* clefts, which occur more commonly when the palate is involved (Genisca et al., 2009), are defined by the presence of at least one unrelated

defect of another organ system or body part that also has surgical, medical, or serious cosmetic consequences (Rasmussen et al., 2003). Without another major birth defect, OFCs are classified as *isolated*; a third classification category, *syndromic*, is used in birth defects studies when a single gene or chromosomal etiology has been identified for the cleft. However, this terminology has been applied inconsistently in the literature. Some researchers use the term *nonsyndromic* when referring to isolated clefts and *syndromic* to refer to nonisolated clefts, the latter sometimes being subdivided *into syndromes of known cause*, such as when a single gene disorder or chromosomal anomaly has been diagnosed, and *syndromes of unknown cause (or idiopathic syndromic)* when the specific etiology is undetermined (Watkins et al., 2014). It is important to note that accurate classification of birth defects often requires review by a clinical geneticist, and few birth defects surveillance programs routinely conduct such reviews on all birth defects, including OFCs. The data presented in this report include both isolated and nonisolated cases combined; therefore, caution should be used when comparing these data with other published reports that may be restricted to only isolated cases.

Children with OFCs typically require extensive multidisciplinary team care, especially during infancy and early childhood, and this care may continue throughout life (ACPA, 2009). Their care includes feeding assistance, counseling, plastic/reconstructive surgery, orthodontics and dental care, otolaryngology, speech and audiology, psychosocial, and developmental follow-up. Depending on the cleft type, children may need different services, and the recommended timing of these services may differ (ACPA, 2009).

Due to the high prevalence of OFCs and health care use and costs associated with their treatment, improving the health of these children is an important public health goal. Disparities in prevalence, risk factors, health service use and access to care among children with OFCs recently were identified as public health research priorities by several convened expert groups sponsored by CDC (Yazdy et al., 2007). Evidence suggests that the three cleft phenotypes differ in etiology (especially for preventable risk factors), recurrence risk, treatment and management, and health service use (Harville et al., 2005; Cassell et al., 2008; ACPA, 2009; Boulet et al., 2009; Weiss et al., 2009).

DATA PRESENTATION OF OROFACIAL CLEFTS

Table 2 presents the counts and prevalence for OFCs from 2007 to 2011 by case-finding methodology and pregnancy outcome from 29 population-based birth defects surveillance programs in the United States. Data are also presented in Table 2 for each phenotype and combined total (cleft lip alone, cleft lip with cleft palate, and cleft palate alone) by maternal race/ethnicity, maternal age, and infant sex. A graphic display of the prevalence of OFCs by maternal race/ethnicity is shown in Figure 1 and by maternal age (years) in Figure 2. Table 3 further stratifies the prevalence of OFCs by presenting a cross-tabulation of each OFC phenotype and combined total by maternal race/ethnicity and maternal age (years).

Infant sex-specific prevalence by maternal race/ethnicity and maternal age for each OFC phenotype is shown in Table 4. The 14 contributing states for Table 4 are a subset of the 29 states included in Tables 2 and 3.

Orofacial Cleft Discussion

OBSERVED PREVALENCE

The prevalence for cleft lip alone is 3.1 per 10,000 live births, 5.6 per 10,000 live births for cleft lip with cleft palate, and 5.9 per 10,000 live births for cleft palate alone. The overall unadjusted prevalence of all OFCs is 14.5, or approximately 1 in 690 births. Separating cleft lip with or without cleft palate into two categories results in approximately one-third of the cases as cleft lip alone and two-thirds as cleft lip with cleft palate. The prevalence of cleft lip with or without cleft palate is similar when compared with the data collected for the 2013 NBDPN annual report (results not shown).

Worldwide, the prevalence of OFCs varies considerably. However, it is not clear to what extent differences in case ascertainment, case definition, and other surveillance methods versus true differences in population prevalence contribute to the geographic variability (IPDTC, 2011; Mossey and Little, 2002). For example, the birth prevalence of cleft lip with or without cleft palate in Japan is 20.0 per 10,000 births—approximately twice the prevalence reported in the United States, Canada, and Australia (IPDTC, 2011). Internationally, the birth prevalence of cleft palate shows even more striking geographic variation, with a 10- to 20-fold difference being reported, although it is likely that much of this variation is due to the difficulty in diagnosing some forms of cleft palate during the newborn period (Mossey and Modell, 2012).

RISK FACTORS

Orofacial clefts have a multifactorial etiology, involving a combination of both genetic and environmental risk factors, and complex gene-environment interaction, which are poorly understood. Several putative risk factors have been identified that tend to vary according to cleft phenotype. Many of these risk factors are preventable, notably maternal smoking (Little et al., 2004; Honein et al., 2007; US DHHS, 2014), alcohol consumption (Lorente et al., 2000; Romitti et al., 2007), diabetes and obesity (Cedergren and Kallen, 2005; Correa et al., 2008; Villamor et al., 2008), maternal diet (Munger, 2002), and certain medications (Hernandez-Diaz et al., 2000; Holmes et al., 2004; Werler et al., 2011; Margulis et al., 2012). In this report, we examine prevalence of OFCs by maternal race/ethnicity, maternal age, and infant sex.

MATERNAL RACE/ETHNICITY

The overall estimated prevalence for OFCs for non-Hispanic whites was 15.4 per 10,000 live births (Table 2). Compared with non-Hispanic whites, the prevalence was relatively similar for Hispanics (14.9 per 10,000 live births) and lower for other racial/ethnic groups except for non-Hispanic American Indians/Alaska Natives (20.5 per 10,000 live births). However, results should be interpreted with caution for the prevalence of OFCs for non-Hispanic American Indians/Alaska Natives due to small numbers.

The variation differed when examining the prevalence by OFC phenotypes. Compared with non-Hispanic whites, the estimated prevalence of each OFC phenotype for non-Hispanic blacks remained significantly lower while for non-Hispanic Asians/Pacific Islanders, the

prevalence was slightly lower or not statistically significant. The prevalence of cleft lip with cleft palate was significantly higher for both Hispanics and non-Hispanic American Indians/Alaska Natives compared with non-Hispanic whites while the observed prevalence for cleft lip alone and cleft palate alone among Hispanics was significantly lower but the increased prevalence among non-Hispanic American Indians/Alaska Natives was nonsignificant (Table 2 and Fig. 1).

Published studies showing OFCs by maternal race/ethnicity varied in several methodological aspects, including: (1) study population (for example: live births, live births and fetuses, inpatient admissions); (2) time periods; (3) geography; (4) case classification (for example: overall cleft cases, cleft lip with and without cleft palate, cleft lip alone, cleft palate alone, isolated cases); and (5) inclusion or exclusion of Hispanic ethnicity and the source of ethnicity information. Despite these differences, statistically significant observations for various case classifications consistently noted lower occurrence in non-Hispanic blacks compared with non-Hispanic whites and Hispanics (Kirby et al., 2000; Genisca et al., 2009; Lebby et al., 2010). Several studies that have examined a broader range of maternal racial/ethnic groups reported similar findings, but also showed non-Hispanic American Indians/Alaska Natives with the highest occurrence of OFCs (Croen et al., 1998; Hashmi et al., 2005; Canfield et al., 2014). Consistent findings were seen with a lower prevalence of cleft palate alone among Hispanics compared with non-Hispanic whites; however, the prevalence for cleft lip alone varied depending on case classification. The studies reporting combined cleft lip with or without cleft palate showed no difference or a slight increase in the prevalence of OFCs among Hispanics compared with non-Hispanic whites. Genisca et al. (2009) presented estimated prevalences for the three OFC phenotypes by three maternal race/ethnicity categories (non-Hispanic white, non-Hispanic black, and Hispanic) and found a decreased prevalence among Hispanics for cleft lip alone and a nonsignificant but slightly higher prevalence for cleft lip with cleft palate. We had similar findings except the prevalence for cleft lip with cleft palate was significantly higher among Hispanics compared with non-Hispanic whites. A strength of our study was the ability to examine the three OFC phenotypes by the five maternal U.S. Census racial/ethnic groups.

MATERNAL AGE

We found that mothers who were greater than or equal to 35 years old had a higher prevalence of OFCs compared with those less than 35 years old. The prevalence for cleft lip alone and cleft lip with cleft palate was relatively stable across all maternal ages except that the prevalence was higher in mothers 40+ years old. For cleft palate alone, the prevalence increased with advanced maternal age, and the prevalence for mothers who were 40+ years old was approximately two-thirds higher than that of mothers less than 20 years old (Table 2 and Fig. 2). This may be due, in part, to the higher rate of certain chromosomal birth defects among older women, such as trisomy 18 and trisomy 13, which are often associated with cleft palate.

Published studies showed inconsistent findings between maternal age and OFCs. Some reported an increase in prevalence with advanced maternal age, while others reported no evidence of an association (Vieira et al., 2002; Bille et al., 2005). One study using data from

a surveillance program found a statistically significant increase of isolated cleft lip with or without cleft palate among infants of mothers less than 20 years old but this was not observed for nonisolated cleft lip (DeRoo et al., 2003).

In general, our data showed the observed crude prevalence of OFCs was higher among mothers age 35 years and older within each racial/ethnic category with some exceptions (Table 3). For cleft lip with cleft palate among non-Hispanic whites and for cleft lip alone among non-Hispanic whites and non-Hispanic blacks, the prevalence was relatively similar between the maternal age categories.

INFANT SEX

The data in Table 2 indicated a higher prevalence of cleft lip alone, cleft lip with cleft palate, and overall for OFCs among males compared with females, but the prevalence was lower for cleft palate alone. Previous literature supports our results (Shaw et al., 1991; Forrester and Merz, 2004; Genisca et al., 2009; Messer et al., 2010;).

Table 4 presents the sex-specific prevalence of OFCs by maternal race/ethnicity and maternal age for 14 states, a subset of the 29 contributing states for this report. These findings are consistent with the previous literature that prevalence differs among the cleft phenotypes by infant sex and maternal race/ethnicity (Shaw et al., 1991; Croen et al., 1998; Kirby et al., 2000; Forrester and Merz, 2004; Hashmi et al., 2005; Genisca et al., 2009; Lebby et al., 2010; Messer et al., 2010; Canfield et al., 2014).

Conclusion

The 2014 NBDPN Congenital Malformations Surveillance Report, which includes data from 39 population-based surveillance programs, continues to provide unique and important information to aid in the understanding of the occurrence and public health importance of birth defects in the United States. The focus on OFCs in the present report, using pooled surveillance data from 29 states, is intended to provide more detailed information on the occurrence of these serious birth defects. We hope the current population-based prevalence estimates of cleft lip alone, cleft lip with cleft palate, and cleft palate alone by maternal race/ethnicity, maternal age, and infant sex in the United States will provide those using this report with the in-depth data they seek. This information can also guide clinicians, scientists, and public health officials concerned with treatment, management, and service planning for children with orofacial clefts.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

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Outcomes Reporting System; Kansas Birth Defects Information System; Kentucky Birth Surveillance Registry; Louisiana Birth Defects Monitoring Network; Massachusetts Center for Birth Defects Research and Prevention; Maryland Birth Defects Reporting and Information System; Maine Birth Defects Program; Michigan Birth Defects Registry; Minnesota Birth Defects Information System; Mississippi Birth Defects Registry; North Carolina Birth Defects Monitoring Program; North Dakota Birth Defects Monitoring System; Nebraska Birth Defects Registry; New Hampshire Birth Conditions Program; New Jersey Special Child Health Services Registry; Nevada Birth Outcomes Monitoring System; New York State Congenital Malformations Registry; Ohio Connections for Children with Special Needs; Oklahoma Birth Defects Registry; Puerto Rico Birth Defects Surveillance and Prevention System; Rhode Island Birth Defects Program; South Carolina Birth Defects Program; Tennessee Birth Defects Registry; Texas Birth Defects Epidemiology and Surveillance Branch; Utah Birth Defect Network; Virginia Congenital Anomalies Reporting and Education System; Vermont Birth Information Network; Wisconsin Birth Defects Registry; and West Virginia Congenital Abnormalities Registry, Education and Surveillance System.

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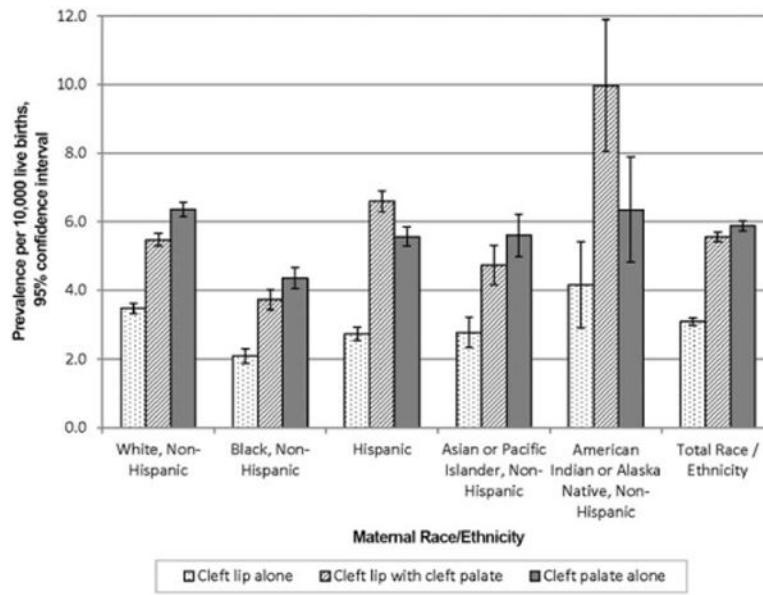


FIGURE 1. Prevalence of orofacial clefts by maternal race/ethnicity, 29 U.S. states, 2007 to 2011.

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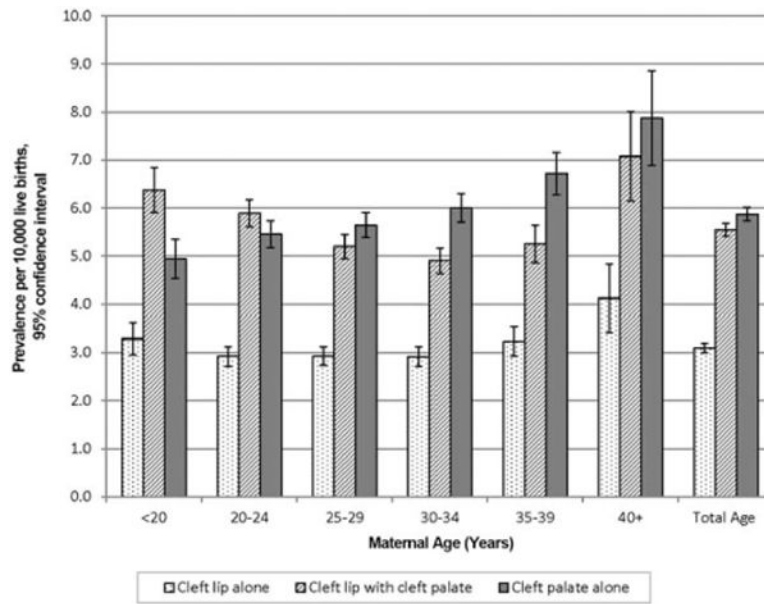


FIGURE 2. Prevalence of orofacial clefts by maternal age (years), 29 U.S. states, 2007 to 2011.

TABLE 1

Disease Classification Codes for Major Birth Defects Included in the 2014 NBDPN Annual Report

Birth defects	ICD-9-CM codes	CDC/BPA codes
Central nervous system		
Anencephaly	740.0 – 740.1	740.00 – 740.10
Spina bifida without anencephaly	741.0, 741.9 w/o 740.0 – 740.1	741.00 – 741.99 w/o 740.00 – 740.10
Encephalocele	742.0	742.00 – 742.09
Holoprosencephaly	742.2	742.26
Eye		
Anophthalmia/microphthalmia	743.0, 743.1	743.00 – 743.10
Congenital cataract	743.30 – 743.34	743.32
Ear		
Anotia/microtia	744.01, 744.23	744.01, 744.21
Cardiovascular		
Common truncus (truncus arteriosus)	745.0	745.00 (excluding 745.01)
Transposition of the great arteries (TGA)	745.10, .12, .19	745.10 – 745.12, 745.18 – 745.19
dextro-Transposition of great arteries (d-TGA) – for CCHD screening ^d	745.10	745.10, 745.11, 745.19
Tetralogy of Fallot	745.2	745.20 – 745.21, 747.31
Ventricular septal defect	745.4	745.40 – 745.49 (excluding 745.487, 745.498)
Atrial septal defect	745.5	745.51 – 745.59
Atrioventricular septal defect (endocardial cushion defect)	745.60, .61, .69	745.60 – 745.69, 745.487
Pulmonary valve atresia and stenosis	746.01, 746.02	746.00, 746.01
Pulmonary valve atresia – for CCHD screening ^d	746.01	746.00
Tricuspid valve atresia and stenosis	746.1	746.100, 746.106 (excluding 746.105)
Tricuspid valve atresia– for CCHD screening ^d	746.1	746.100
Ebstein anomaly	746.2	746.20
Aortic valve stenosis	746.3	746.30
Hypoplastic left heart syndrome	746.7	746.70
Coarctation of aorta	747.10	747.10 – 747.19
Total anomalous pulmonary venous connection	747.41	747.42
Single ventricle	745.3	745.3
Interrupted aortic arch	747.11	747.215 – 747.217
Double outlet right ventricle	745.11	745.13 – 745.15
Orofacial		
Cleft palate alone (without cleft lip)	749.0	749.00 – 749.09
Cleft lip alone (without cleft palate)	749.1	749.10 – 749.19
Cleft lip with cleft palate	749.20–749.25	749.20 – 749.29
Choanal atresia	748.0	748.00

Birth defects	ICD-9-CM codes	CDC/BPA codes
Gastrointestinal		
Esophageal atresia/tracheoesophageal fistula	750.3	750.30 – 750.35
Rectal and large intestinal atresia/stenosis	751.2	751.20 – 751.24
Biliary atresia	751.61	751.65
Small intestinal atresia/stenosis	751.1	751.10 – 751.19
Genitourinary		
Renal agenesis/hypoplasia	753.0	753.00 – 753.01
Bladder exstrophy	753.5	753.50
Hypospadias	752.61	752.60 – 752.62(excluding 752.61 and 752.621)
Congenital posterior urethral valves	753.6	753.60
Cloacal exstrophy	751.5	751.555
Musculoskeletal		
Gastroschisis	756.73 (as of 10/1/09)	756.71
Omphalocele	756.72 (as of 10/1/09)	756.70
Diaphragmatic hernia	756.6	756.610 – 756.617
Limb deficiencies (reduction defects)	755.2 – 755.4	755.20 – 755.49
Craniosynostosis	No specific code	756.00 – 756.03
Clubfoot	754.51, 754.70	754.50, 754.73(excluding 754.735)
Chromosomal		
Trisomy 13	758.1	758.10 – 758.19
Trisomy 21 (Down syndrome)	758.0	758.00 – 758.09
Trisomy 18	758.2	758.20 – 758.29
Turner syndrome	758.6	758.60 – 758.69
Deletion 22q11.2	758.32	758.37

ICD-9-CM, International Classification of Diseases, 9th Revision, Clinical Modification; CDC/BPA, Centers for Disease Control and Prevention/ British Pediatric Association Classification of Diseases; NBDPN, National Birth Defects Prevention Network; w/o, without; CCHD, critical congenital heart defect.

^aThe primary targets for CCHD screening include 7 conditions: hypoplastic left heart syndrome, pulmonary atresia with intact septum, tetralogy of Fallot, total anomalous pulmonary venous connection, dextro-transposition of great arteries (d-TGA), tricuspid atresia, and truncus arteriosus. The NBDPN traditionally monitors all TGA, and both atresia and stenosis for pulmonary and tricuspid valve conditions; however, for CCHD screening reporting purpose, these conditions are also reported as d-TGA, pulmonary valve atresia, and tricuspid valve atresia.

Orofacial Cleft Counts, Prevalence and 95% Confidence Interval for 29 U.S. States, 2007 to 2011 (Prevalence per 10,000 Live Births)^a

TABLE 2

	Cleft lip alone		Cleft lip with cleft palate		Cleft palate alone		Total	
	n	Prevalence (95% CI)	n	Prevalence (95% CI)	n	Prevalence (95% CI)	n	Prevalence (95% CI)
Total Cases	3,509	3.1 (3.0, 3.2)	6,286	5.6 (5.4, 5.7)	6,651	5.9 (5.7, 6.0)	16,446	14.5 (14.3, 14.8)
Case-finding methodology^b								
Active case finding	1,354	3.3 (3.1, 3.5)	2,659	6.5 (6.3, 6.7)	2,495	6.1 (5.9, 6.3)	6,508	15.9 (15.5, 16.3)
Passive case finding	2,155	3.0 (2.9, 3.1)	3,627	5.0 (4.9, 5.2)	4,156	5.7 (5.6, 5.9)	9,938	13.7 (13.5, 14.0)
Pregnancy outcome inclusion^c								
Live births only	916	2.7 (2.6, 2.9)	1,574	4.7 (4.5, 4.9)	1,823	5.4 (5.2, 5.7)	4,313	12.9 (12.5, 13.3)
Live births and stillbirths	1,423	3.1 (2.9, 3.3)	2,427	5.3 (5.1, 5.5)	2,587	5.6 (5.4, 5.9)	6,437	14.0 (13.7, 14.4)
All pregnancy outcomes	1,170	3.5 (3.3, 3.7)	2,285	6.8 (6.5, 7.0)	2,241	6.6 (6.4, 6.9)	5,696	16.8 (16.4, 17.3)
Maternal Race/ethnicity^d								
White, Non-Hispanic	2,091	3.5 (3.3, 3.6)	3,292	5.5 (5.3, 5.7)	3,822	6.4 (6.2, 6.6)	9,205	15.4 (15.0, 15.7)
Black, Non-Hispanic	381	2.1 (1.9, 2.3)	678	3.7 (3.5, 4.0)	789	4.4 (4.1, 4.7)	1,848	10.2 (9.7, 10.7)
Hispanic	746	2.8 (2.6, 3.0)	1,793	6.6 (6.3, 6.9)	1,510	5.6 (5.3, 5.9)	4,049	14.9 (14.5, 15.4)
Asian or Pacific Islander, Non-Hispanic	156	2.8 (2.3, 3.2)	266	4.7 (4.2, 5.3)	315	5.6 (5.0, 6.2)	737	13.2 (12.2, 14.1)
American Indian or Alaska Native, Non-Hispanic	43	4.2 (2.9, 5.4)	104	10.1 (8.1, 12.0)	66	6.4 (4.8, 7.9)	213	20.5 (17.7, 23.2)
Maternal Age (years)^d								
<20	371	3.3 (3.0, 3.6)	718	6.4 (5.9, 6.9)	557	5.0 (4.5, 5.4)	1,646	14.6 (13.9, 15.3)
20–24	807	2.9 (2.7, 3.1)	1,627	5.9 (5.6, 6.2)	1,506	5.5 (5.2, 5.7)	3,940	14.3 (13.8, 14.7)
25–29	927	2.9 (2.7, 3.1)	1,649	5.2 (5.0, 5.5)	1,790	5.7 (5.4, 5.9)	4,366	13.8 (13.4, 14.2)
30–34	772	2.9 (2.7, 3.1)	1,297	4.9 (4.6, 5.2)	1,588	6.0 (5.7, 6.3)	3,657	13.8 (13.4, 14.3)
35–39	426	3.2 (2.9, 3.5)	692	5.3 (4.9, 5.7)	884	6.7 (6.3, 7.2)	2,002	15.2 (14.5, 15.9)
40+	130	4.1 (3.4, 4.8)	223	7.1 (6.2, 8.0)	250	7.9 (7.0, 8.9)	603	19.1 (17.6, 20.7)
Infant Sex^d								
Male	2,107	3.6 (3.5, 3.8)	3,810	6.6 (6.4, 6.8)	3,017	5.2 (5.0, 5.4)	8,934	15.4 (15.1, 15.7)
Female	1,390	2.5 (2.4, 2.6)	2,453	4.4 (4.3, 4.6)	3,622	6.5 (6.3, 6.8)	7,465	13.5 (13.2, 13.8)

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CI: Confidence interval

^a Contributing states included: AR, AZ, CO, FL, GA, IA, IL, KS, KY, MA, ME, MI, MN, MS, NC, NE, NJ, NV, NY, OK, PR, RI, TN, VA, VT, and WI; LA provided data for 2007–2010 only, OH for 2008 only, and TX for 2007–2009 only.

^b Program primary case-finding methodology: Active case-finding: AR, AZ, GA, IA, LA, MA, MN, NC, OK, PR, TX; Passive case-finding: CO, FL, IL, KS, KY, ME, MI, MS, NE, NJ, NV, NY, OH, RI, TN, VA, VT, WI

^c Program case inclusion: Live births only: FL, LA, MN, NJ, NV, NY, VT; Live births and stillbirths: AZ, IL, KS, KY, MA, ME, MI, MS, NE, OH, TN, VA, WI; All pregnancy outcomes: AR, CO, GA, IA, NC, OK, PR, RI, TX

^d Counts of unknown and/or other are not reported for Maternal Race/ethnicity, Maternal Age, and Infant sex

Orofacial Cleft Counts and Prevalence by Maternal Race/Ethnicity and Age, 29 U.S. States, 2007 to 2011 (Prevalence per 10,000 Live Births)^a

TABLE 3

Maternal Age (years)	Maternal Race/Ethnicity											
	White, Non-Hispanic		Black, Non-Hispanic		Hispanic		Asian or Pacific Islander, Non-Hispanic		American Indian or Alaska Native, Non-Hispanic		Total race/ethnicity ^b	
	n	Prevalence	n	Prevalence	n	Prevalence	n	Prevalence	n	Prevalence	n	Prevalence
Cleft lip alone												
<35	1737	3.5	336	2.1	621	2.6	106	2.4	38	4.0	2877	3.0
35+	344	3.6	41	2.1	100	3.2	49	4.1	5	6.3	556	3.4
Total Age ^b	2091	3.5	381	2.1	746	2.8	156	2.8	43	4.2	3509	3.1
Cleft lip with cleft palate												
<35	2788	5.5	594	3.7	1542	6.4	188	4.3	NR	NR	5291	5.5
35+	495	5.2	82	4.2	242	7.7	77	6.4	NR	NR	915	5.6
Total Age ^b	3292	5.5	678	3.7	1793	6.6	266	4.7	104	10.3	6286	5.6
Cleft palate alone												
<35	3139	6.2	678	4.2	1260	5.3	234	5.3	59	6.1	5441	5.6
35+	676	7.1	108	5.5	238	7.5	80.0	6.6	7.0	8.8	1134	7.0
Total Age ^b	3822	6.4	789	4.4	1510	5.6	315	5.6	66	6.5	6651	5.9

NR: Not reported due to small counts for selected category.

^aContributing states included: AR, AZ, CO, FL, GA, IA, IL, KS, KY, MA, ME, MI, MN, MS, NC, NE, NJ, NV, NY, OK, PR, RI, TN, VA, VT, and WI; LA provided data for 2007–2010 only, OH for 2008 only, and TX for 2007–2009 only.

^bTotal included unknown and/or other.

Sex-specific Counts and Prevalence of Orofacial Clefts by Maternal Race/Ethnicity and Age, 14 U.S. States, 2007 to 2011 (Prevalence per 10,000 Live Births)^a

TABLE 4

Maternal Race/Ethnicity	Infant sex						
	Male			Female			Total infant sex
	n	Prevalence	n	Prevalence	n	Prevalence	
Cleft lip alone							
White, Non-Hispanic	730	4.2	388	2.3	1119	3.3	
Black, Non-Hispanic	91	1.7	104	2	195	1.8	
Hispanic	166	2.6	123	2	289	2.3	
Asian or Pacific Islander, Non-Hispanic	53	2.6	47	2.5	100	2.6	
American Indian or Alaska Native, Non-Hispanic	3	4.0	1	1.4	4	2.7	
Total Race/Ethnicity ^b	1069	3.3	679	2.2	1749	2.8	
Cleft lip with cleft palate							
White, Non-Hispanic	1159	6.7	662	4	1826	5.4	
Black, Non-Hispanic	189	3.5	184	3.5	373	3.5	
Hispanic	467	7.2	322	5.2	791	6.2	
Asian or Pacific Islander, Non-Hispanic	98	4.9	79	4.2	177	4.5	
American Indian or Alaska Native, Non-Hispanic	6	7.9	8	10.8	14	9.4	
Total Race/Ethnicity ^b	1949	6.1	1283	4.2	3239	5.2	
Cleft palate alone							
White, Non-Hispanic	1022	5.9	1174	7.1	2196	6.5	
Black, Non-Hispanic	216	4.0	257	4.9	473	4.4	
Hispanic	305	4.7	391	6.3	696	5.5	
Asian or Pacific Islander, Non-Hispanic	94	4.7	119	6.3	213	5.5	
American Indian or Alaska Native, Non-Hispanic	NR		NR		NR	NR	
Total Race/Ethnicity ^b	1672	5.2	1978	6.5	3651	5.9	
Maternal Age (in years)							

	Infant sex					
	Male			Female		
	n	Prevalence	n	Prevalence	n	Prevalence
Cleft lip alone						
<35	862	3.2	551	2.2	1414	2.7
35+	196	3.8	121	2.4	317	3.1
Total Age ^b	1069	3.3	679	2.2	1749	2.8
Cleft lip with cleft palate						
<35	1655	6.2	1048	4.1	2710	5.2
35+	291	5.6	229	4.6	520	5.1
Total Age ^b	1949	6.1	1283	4.2	3239	5.2
Cleft palate alone						
<35	1351	5.1	1600	6.3	2951	5.6
35+	312	6.0	372	7.5	685	6.8
Total Age ^b	1672	5.2	1978	6.5	3651	5.9

NR: Not reported due to small cell counts.

^aThe contributing state programs for Table 4 are a subset of the 29 state programs used for Tables (2–3). These 14 states include: AR, CO, FL, IL, KS, LA (2007–2010 only), MA, ME, MN, NJ, NY, OH (2008 only), TN, and VA.

^bTotal included unknown and/or other.