

# Orofacial Cleft Prevalence in the United States: Highlighting Ethnic Disparities in the Prevalence of Cleft Lip and Cleft Palate Across 12-Year Period

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## Background



(National Birth Defects Prevention Network Guidelines for Conducting Birth Defects Surveillance.)

Orofacial clefts are among the most common congenital malformations in the United States and worldwide. Cleft prevalence is influenced by a variety of factors, including ethnic background, environmental exposures, maternal age and diet, as well as socioeconomic status predisposing to limited access to prenatal care. Cleft lip with and without cleft palate (CL+/-CP) and cleft palate (CP) alone are the most common orofacial clefts. To highlight its significance, the Centers for Disease Control and Prevention (CDC) has recently recognized orofacial cleft studies as public health research priorities.

## Research Objectives

A comprehensive understanding of the national prevalence of CL and CP is essential to better understand its etiology, identify potential risks factors, and expedite early interventional care for children born with these conditions. Despite its indisputable clinical value, accurate national wide population-based data on orofacial clefts in the United States have not been reported since 2006. Our goal is to provide data on national prevalence and evaluate ethnic differences in orofacial cleft birth rates.

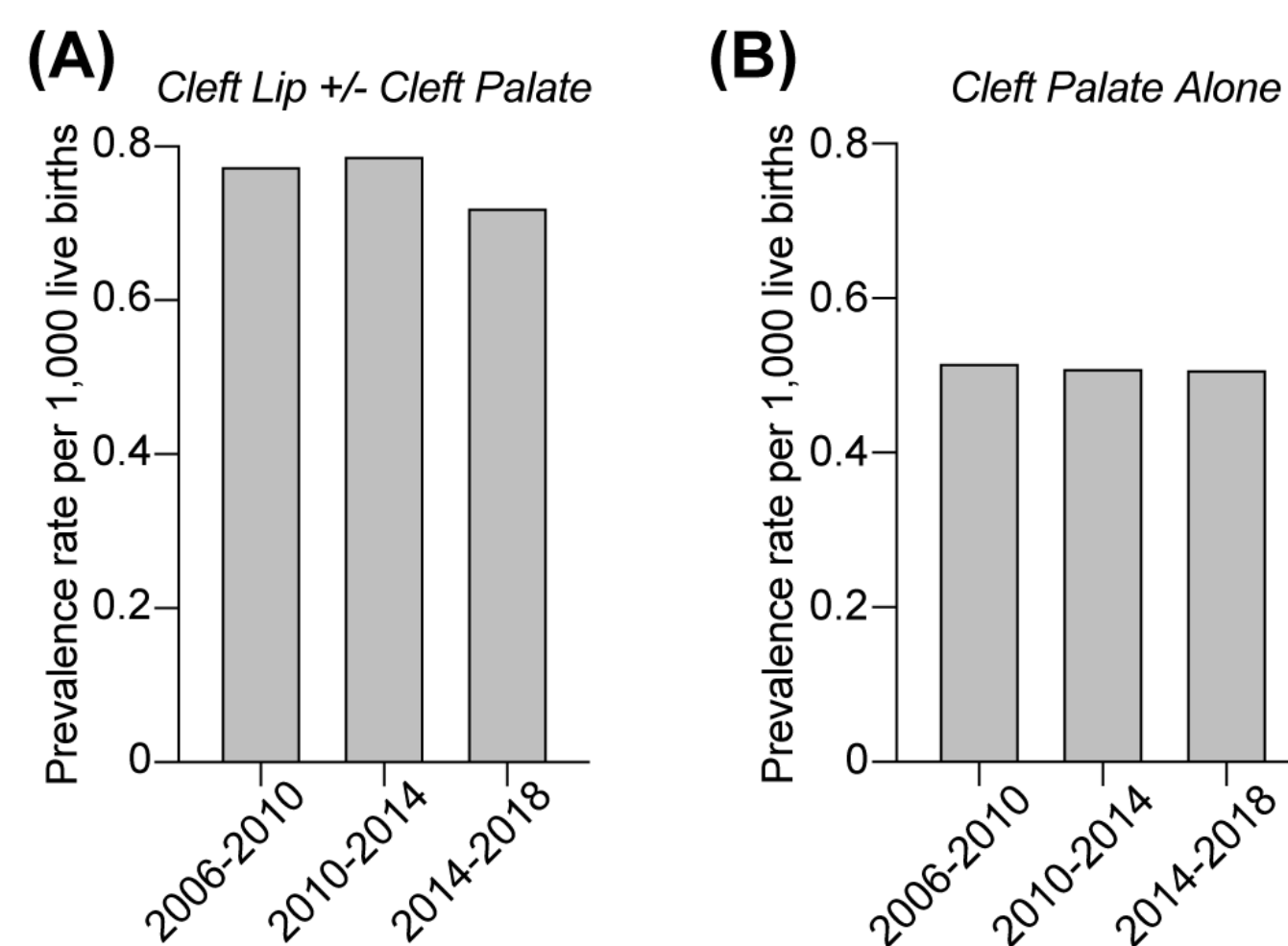
## Methods

Data originating from the National Birth Defect Prevention Network (NBDPN) database spanning three intervals: 2006-2010, 2010-2014, and 2014-2018 were used to evaluate trends in orofacial cleft births in the United States. ICD 9 and 10 codes (Table 1) were used from NBDPN contributors to report cases. The number of cases for cleft lip with and without cleft palate (CL+/-CP) and cleft palate (CP) alone were sub-stratified by ethnic category. Live birth statistics in the studied time periods were extracted from the CDC database. Prevalence rates were calculated using the total live births reported in each maternal ethnic group and compared to the trends in non-Hispanic Whites, cumulatively across all years. Prevalence was calculated as the count of cases in each subgroup—regardless of pregnancy outcome (i.e., live birth, stillbirth, spontaneous/elective termination)—divided by the total number of live births within the same subgroup, and then multiplied by 1,000. We adjusted all prevalence rates to per 1,000 births to stay in line with traditional methodology for reporting orofacial cleft incidence

	Diagnosis codes				
	Before 2015		After 2015		
	ICD-9-CM	CDC/BPA	ICD-9-CM	ICD-10-CM	CDC/BPA
CP	749	749.00-749.09	749	Q35.1-Q35.9	749.00-749.09
CL+/-CP	749.1-749.2	749.10-749.29	749.20-749.25	Q37.0-Q37.9	749.20-749.29
CL			749.1	Q36.0-Q36.9	749.10-749.19

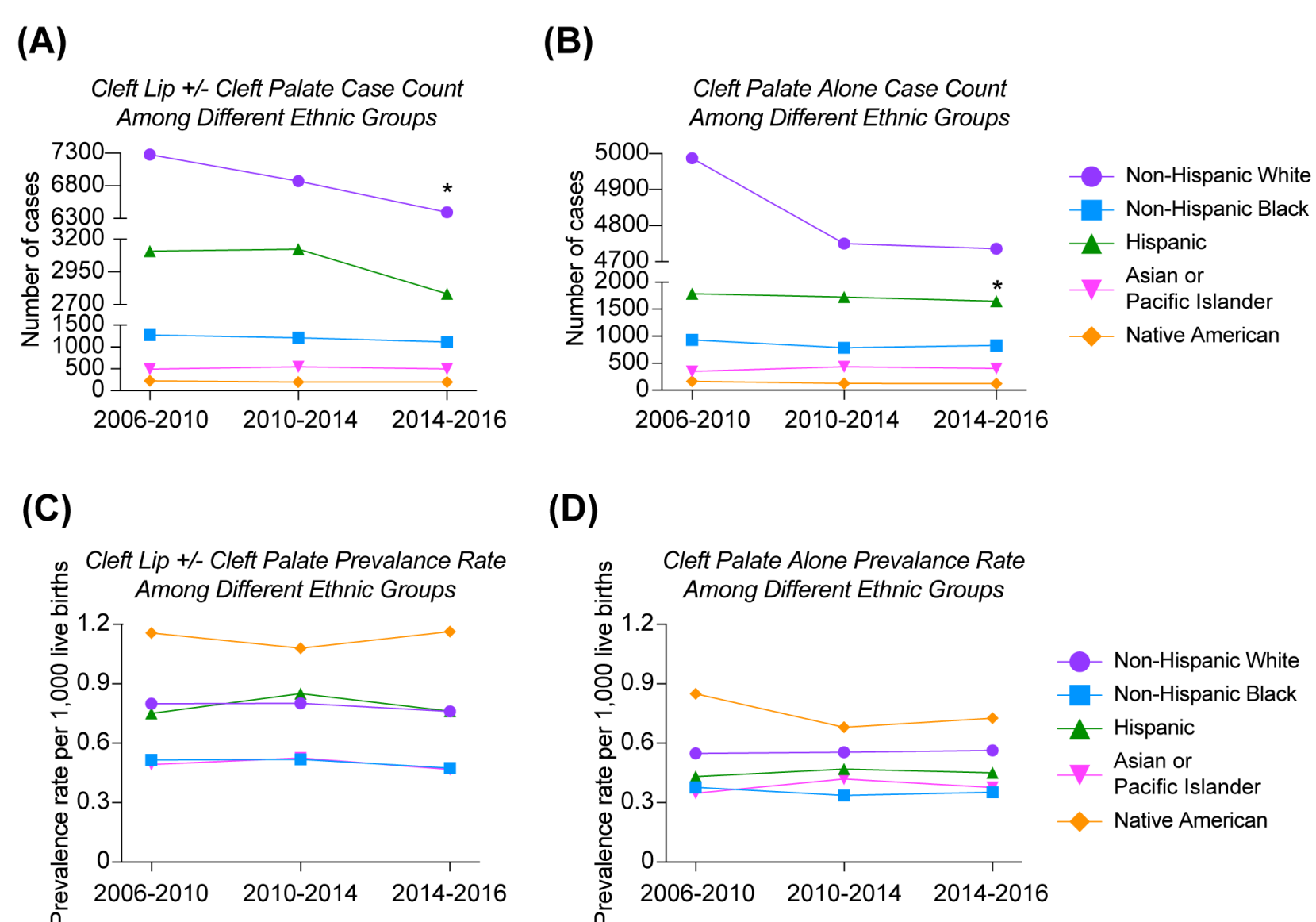
Table 1. List of diagnosis codes used to identify patients with orofacial clefts before and after 2015.

## Figure 1. National Cleft Birth Rate Adjusted for National Birth Count from 2006 to 2018



(A, B) The prevalence rate of children diagnosed with CL+/-CP and (B) CP alone per 1,000 live births in the same period. CL, cleft lip; CL+/-CP, cleft lip with or without cleft palate; CP, cleft palate.

## Figure 2. Trends of Children Born with Orofacial Clefts Across Ethnic Groups.



(A, B) Total raw counts of (A) CL+/-CP and (B) CP alone from 2006 to 2018, subdivided by race. (C, D) Prevalence rates of (C) CL+/-CP and (D) CP alone within each ethnic group per 1,000 live births in that ethnic group, from 2006 to 2018. In (A) and (B) asterisks indicate statically significant trends.

## Results

Calculated incidence rates, adjusted for national birth counts, show that:

- Native Americans/Alaskan Natives were 43.8% more likely to have CL+/-CP (95% CI [1.33-1.56],  $p < 0.0001$ ) and 36% more likely to have CP alone (95% CI [1.23-1.50],  $p < 0.0001$ ) compared to non-Hispanic Whites.
- Incidence of CL+/-CP in non-Hispanic Blacks (OR=0.64, 95% CI [0.62-0.66]) and Asians/Pacific Islanders (OR=0.63, 95% CI [0.60-0.66]) were significantly lower than in non-Hispanic Whites ( $p < 0.0001$ ).
- Prevalence rates of CP alone were significantly lower in non-Hispanic Blacks (OR=0.64, 95% CI [0.61-0.67],  $p < 0.0001$ ), Asians/Pacific Islanders (OR=0.69, 95% CI [0.65-0.73],  $p < 0.0001$ ), and Hispanics (OR=0.81, 95% CI [0.79, 0.84],  $p < 0.0001$ ).

## Limitations

The data reported here will be the most complete to-date analysis of national CL and CP counts. However, we acknowledge that underreporting the prevalence of cleft cases is still a limitation of this study, as not all states report congenital defects to the National Birth Defect Prevention Network. The number of states that have been submitting complete data has been increasing every year, with almost total participation in recent years. We also acknowledge that due to the reporting style of the NBDPN, all statistics are in increments of four years, which invariably lowers some statistical power. Of note, the cleft data presented in this report include both isolated and nonisolated (or non-syndromic and syndromic, respectively) cases combined. This should be considered when comparing these data with other published reports that may only report isolated cases.

## Conclusions

Improving the time to surgery and aligning care teams for children with CL and CP is not only an important goal for plastic and reconstructive surgeons, but it is also a public health interest. Understanding the national burden of orofacial clefts, and the populations most at risk, as well as how these numbers are changing, can help surgeons and cleft care teams align resources and better predict health care use and costs associated with treatment for these children.

Our study shows the most recent trends in orofacial cleft burden nationally and across racial and ethnic groups, with adjustments for a decreasing national birth count. The findings here show higher rates of CL+/-CP as well as CP alone in children identifying as Native American and Alaskan Native compared to non-Hispanic Whites. This research can guide surgeons to think critically about disparities in incidence and risk factors. Nevertheless, more research should be pursued to identify causative factors for these differences in cleft rates among ethnic groups, as well as health service use and access to care among children with orofacial clefts.