

## **Major Birth Defects Data from Population-based Birth Defects Surveillance Programs in the United States, 2014-2018**

### **Intro**

The first Congenital Malformations Surveillance Report was published by the National Birth Defects Prevention Network (NBDPN) in 1997. The NBDPN then began publishing state-specific counts and prevalence of birth defects and a directory of state-based birth defects surveillance programs on an annual basis in 2000. This information was first published in the journal Birth Defects Research Part A and later in the journal Birth Defects Research. Beginning in 2022, this same data will be published on a biennial basis on the NBDPN website (nbdpn.org).

### **Data Collection**

The call for data for the 2021 report was distributed in April 2021 to population-based birth defects surveillance systems by the National Birth Defects Prevention Network (NBDPN) Data Committee. Surveillance programs were provided with a data dictionary, and data collection tools that facilitated data collection.

Participating programs submitted data on case counts and live births occurring from January 1, 2014 to December 31, 2018. Case data was requested for the 47 major birth defects in Table 1 by the following maternal and infant covariates: maternal race/ethnicity, maternal age at birth, year of birth, and infant sex. Pregnancy outcome of the case was also submitted for select programs or birth defects. Similar covariates were collected for live birth denominator data with the exception of pregnancy outcome.

The values submitted for maternal race/ethnicity were stratified by the US. Census groups: non-Hispanic white, non-Hispanic black, Hispanic, non-Hispanic Asian/Pacific Islander, non-Hispanic American Indian/Alaska Native, and other/unknown. Maternal age at birth was grouped into seven categories: <20, 20-24, 25-29, 30-34, 35-39, 40+ and unknown. For infant sex cases were classified as either male, female, or unknown. The categories used for pregnancy outcome were live births, fetal deaths, terminations, unspecified non-live births, and unknown. Data was submitted in either SAS or Microsoft Excel.

Birth defects surveillance programs also submitted information for the program directory regarding case definition, surveillance methods, case ascertainment, data collection procedures, data analysis, funding, and program contact information. Material for the directory was collected using a standardized form.

### **Data presentation**

Program-specific data is presented in two tables a) counts and prevalences for the 47 major birth defects by the maternal race/ethnicity categories provided above and b) counts and prevalences for selected birth defects in the chromosomal and musculoskeletal organ systems by two maternal age categories (less than 35 years, and 35+ years). Prevalence for all birth defects in table 1 except Turner syndrome, congenital posterior urethral valves, and hypospadias is calculated as, the number of cases of each birth defect within each stratum (the numerator) divided by the total number of live births within each stratum (the denominator), multiplied by 10,000. For Turner syndrome female live births are used as the denominator in prevalence calculations, for congenital posterior urethral valves and hypospadias male live births are used as the denominator.

Data quality checks and data analysis were performed using SAS Version 9.4 (SAS Institute, Cary, NC). Due to variation in surveillance methodologies used by participating programs, footnotes are provided for each table indicating where programs may have used different definitions or inclusion/exclusion criteria than those specified by NBDPN. A more in-depth description of the case-ascertainment methodology, birth outcomes monitored, data sources used, and other sources of variation between surveillance systems can be found in the program directory. The prepared data tables and directory were approved by the birth defects surveillance programs in October 2021.