



# New Jersey Birth Defect County Profile

## Purpose

- The Profiles were developed to disseminate accurate and timely information for New Jersey infants/children with birth defects. Having county based birth defects will assist organizations, agencies, individuals, and other interested parties in obtaining relevant information particular to identified needs and risk factors.
- The Profiles will also assist in analyzing data on the number of infants/children with birth defects referred and accessing Special Child Health Services Case Management (CM) Services. The completed registration information is shared with the County based county of residence CM unit so that CM can assist families with varied services such as Early Intervention Services (EIS), financial aid, summer camps for children with certain medical needs, help with durable medical equipment, and other services and resources in the county of residence.

## Glossary for County Profile

- Cardiovascular: Aortic valve stenosis, Atrial septal defect, Atrioventricular septal defect (endocardial cushion defect), Coarctation of aorta, Common truncus (truncus arteriosus or TA), Double outlet right ventricle (DORV), Ebstein anomaly, Hypoplastic left heart syndrome, Interrupted aortic arch (IAA), Pulmonary valve atresia and stenosis, Single ventricle, Tetralogy of Fallot (TOF), Transposition of the great arteries (TGA), Dextro-Transposition of great arteries (d-TGA), Total anomalous pulmonary venous connection (TAPVC), Tricuspid valve atresia and stenosis, Ventricular septal defect.
- Central Nervous System (CNS): Anencephaly, Encephalocele, Holoprosencephaly, Spina bifida without anencephaly.
- Chromosomal: Deletion 22 q11.2, Trisomy 13 (Edwards syndrome), Trisomy 18 (Patau syndrome), Trisomy 21 (Down syndrome), Turner syndrome.
- Ear: Anotia/microtia.
- Eye: Anophthalmia/microphthalmia, Congenital cataract.
- Gastrointestinal: Biliary atresia, Esophageal atresia/tracheoesophageal fistula, Rectal and large intestinal atresia/stenosis, Small intestinal atresia/stenosis.
- Genitourinary: Bladder exstrophy, Cloacal exstrophy, Congenital posterior urethral valves, Hypospadias, Renal agenesis/hypoplasia.
- Musculoskeletal: Clubfoot, Craniosynostosis, Diaphragmatic hernia, Gastroschisis, Limb deficiencies (reduction defects), Omphalocele.
- Orofacial: Choanal atresia, Cleft lip alone (without cleft palate), Cleft lip with cleft palate, Cleft palate alone (without cleft lip).

## Data Sources

- Birth Certificate Database, Office of Vital Statistics and Registry, New Jersey Department of Health
- Birth Defect Registry Database, Early Identification and Monitoring Program, Special Child Health and Early Intervention Services, Division of Family Health Services, New Jersey Department of Health

## Early Identification and Monitoring

- Birth Defects & Autism Registry
  - NJ state laws (P.L. 1983 c.291; amended P.L. 2005 c.176) NJSA 26:8-40.20 and (P.L. 2007 c.170) NJSA 26:2-185 mandates reporting of birth defects of children up through 5 years of age and autism up through 21 years of age to the Registry.
  - Infants/children should be registered so that important diagnostic information can be identified for statistical needs and referral to the services for the needs of the family can be made.

## Limitations

- New Jersey birth certificate files are used for denominators and maternal characteristics (age, race, ethnicity) in this profile. The data included here are for New Jersey residents regardless of where the birth occurred. The inclusion of data on births to New Jersey residents which occurred in other states is made possible through the Vital Statistics Cooperative Program (VSCP). The birth data were generated from data files available at the time of preparation of the dataset. Any data pertaining to a birth for which a certificate was filed after that time or relating to corrections or revisions made since the data were processed for the electronic file are not included.
- New Jersey systems do not rely on committed staff to go out and collect the data, but rather rely on agreements to receive reports about birth defects cases from hospitals and other available health care sources. The information from these reports is reviewed and various methods are used to verify the diagnoses of the babies reported to have birth defects. A yearly audit is conducted to ensure that all birthing hospitals are in compliance with the mandate to report birth defects. Additionally, many children are being transferred prior to delivery to an out of state hospital where there is no reciprocity for reporting defects to New Jersey.

## Contact

Additional information or questions for "New Jersey Birth Defect County Profile" by contacting us at [eim.bdars@doh.nj.gov](mailto:eim.bdars@doh.nj.gov) or call 609-292-5676

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