North Carolina

N.C. Birth Defects Monitoring Program (NCBDMP)

Purpose: Surveillance, Research
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Early Childhood Prevention Programs
Program status: Currently collecting data
Start year: 1987
Earliest year of available data: 1989
Organizational location: Department of Health (State Center for Health Statistics)
Population covered annually: 120,000
Statewide: Yes
Current legislation or rule: NCGS 130A-131.16
Legislation year enacted: 1995

Case Definition
Outcomes covered: Major birth defects
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), Elective terminations (All gestational ages)
Age: 1 year
Residence: NC resident births, including out of state deliveries

Surveillance Methods
Case ascertainment: Active Case Finding
Vital records: Birth certificates, Death certificates, Matched birth/death file, Fetal birth certificate
Other state based registries: Newborn metabolic screening program
Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), ICU/NICU logs or charts, Postmortem/pathology logs, Surgery logs, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Specialty outpatient clinics
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Genetic counseling/clinical genetic facilities
Other sources: Positive pulse oximetry screening database

Case Ascertainment
Conditions warranting chart review in newborn period: Any chart with an ICD-9-CM code 740-759/ICD-10-CM code Q00-Q99, Any chart with a selected list of ICD-9-CM codes outside 740-759/ICD-10-CM codes outside Q00-Q99, Any birth certificate with a birth defect box checked, All stillborn infants, All prenatally diagnosed or suspected cases, Failed newborn pulse oximetry screen
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
Coding: CDC coding system based on BPA

Data Collected
Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage
Data collection: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)
Database collection and storage: Access

Data Analysis
Data analysis software: SAS, Access
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Clinical review, Timeliness
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Time trends, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Grant proposals, Education/public awareness, Prevention projects

System Integration
System links: Link to other state registries/databases, Link case finding data to final birth file, Link to environmental databases

Other
Web site: https://schs.dph.ncdhhs.gov/units/bdmp/

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DATA TABLES

North Carolina

Birth Defects Counts and Prevalence 2014 - 2018 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total***	**Notes**
Anencephalus	57	26	16	2	0	119	
	1.7	***1.8***	***1.8***	***0.8***	***0.0***	***2.0***	
Anophthalmia/microphthalmia	45	15	19	3	0	83	
	1.4	***1.0***	***2.1***	***1.2***	***0.0***	***1.4***	
Anotia/microtia	42	10	39	5	4	100	
	1.3	***0.7***	***4.3***	***1.9***	***5.0***	***1.7***	
Aortic valve stenosis	94	21	21	4	5	146	
	2.8	***1.5***	***2.3***	***1.5***	***6.2***	***2.4***	
Atrial septal defect	1,569	774	438	101	58	2,945	
	47.4	***53.8***	***48.1***	***39.1***	***72.3***	***49.0***	
Atrioventricular septal defect (Endocardial cushion defect)	187	107	44	10	5	356	
	5.6	***7.4***	***4.8***	***3.9***	***6.2***	***5.9***	
Biliary atresia	13	24	6	1	2	46	
	0.4	***1.7***	***0.7***	***0.4***	***2.5***	***0.8***	
Bladder exstrophy	7	4	0	1	0	13	
	0.2	***0.3***	***0.0***	***0.4***	***0.0***	***0.2***	
Choanal atresia	44	16	10	3	1	74	
	1.3	***1.1***	***1.1***	***1.2***	***1.2***	***1.2***	
Cleft lip alone	125	46	26	6	3	211	
	3.8	***3.2***	***2.9***	***2.3***	***3.7***	***3.5***	
Cleft lip with cleft palate	171	32	66	14	5	295	
	5.2	***2.2***	***7.2***	***5.4***	***6.2***	***4.9***	
Cleft palate alone	225	56	39	12	5	338	
	6.8	***3.9***	***4.3***	***4.6***	***6.2***	***5.6***	
Cloacal exstrophy	6	3	0	0	0	9	1
	0.2	***0.2***	***0.0***	***0.0***	***0.0***	***0.1***	
Clubfoot	671	266	152	32	17	1,150	
	20.3	***18.5***	***16.7***	***12.4***	***21.2***	***19.1***	
Coarctation of the aorta	181	64	39	6	5	296	
	5.5	***4.5***	***4.3***	***2.3***	***6.2***	***4.9***	
Common truncus (truncus arteriosus)	21	10	10	2	2	45	
	0.6	***0.7***	***1.1***	***0.8***	***2.5***	***0.7***	
Congenital cataract	35	20	9	5	0	70	
	1.1	***1.4***	***1.0***	***1.9***	***0.0***	***1.2***	
Congenital posterior urethral valves	58	31	11	3	1	108	2
	3.4	***4.2***	***2.4***	***2.3***	***2.4***	***3.5***	
Craniosynostosis	197	47	49	4	4	301	
	5.9	***3.3***	***5.4***	***1.5***	***5.0***	***5.0***	
Deletion 22q11.2	23	12	12	2	1	50	
	0.7	***0.8***	***1.3***	***0.8***	***1.2***	***0.8***	
Diaphragmatic hernia	98	53	34	8	5	200	
	3.0	***3.7***	***3.7***	***3.1***	***6.2***	***3.3***	
Double outlet right ventricle	49	20	10	4	0	83	
	1.5	***1.4***	***1.1***	***1.5***	***0.0***	***1.4***	
Ebstein anomaly	18	4	4	0	3	29	
	0.5	***0.3***	***0.4***	***0.0***	***3.7***	***0.5***	
Encephalocele	20	17	4	0	0	47	
	0.6	***1.2***	***0.4***	***0.0***	***0.0***	***0.8***	
Esophageal atresia/tracheoesophageal fistula	92	17	16	5	1	131	
	2.8	***1.2***	***1.8***	***1.9***	***1.2***	***2.2***	
Gastroschisis	152	41	48	7	3	258	
	4.6	***2.9***	***5.3***	***2.7***	***3.7***	***4.3***	
Holoprosencephaly	30	22	17	0	1	75	
	0.9	***1.5***	***1.9***	***0.0***	***1.2***	***1.2***	
Hypoplastic left heart syndrome	71	52	15	4	1	144	
	2.1	***3.6***	***1.6***	***1.5***	***1.2***	***2.4***	
Hypospadias	1,291	446	126	57	37	1,957	2
	75.9	***61.1***	***27.3***	***42.9***	***89.9***	***63.6***	
Interrupted aortic arch	25	10	4	1	1	43	
	0.8	***0.7***	***0.4***	***0.4***	***1.2***	***0.7***	

North Carolina

Birth Defects Counts and Prevalence 2014 - 2018 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total***	**Notes**
Limb deficiencies (reduction defects)	129	66	41	5	5	249	
	3.9	***4.6***	***4.5***	***1.9***	***6.2***	***4.1***	
Omphalocele	88	45	15	2	2	165	
	2.7	***3.1***	***1.6***	***0.8***	***2.5***	***2.7***	
Pulmonary valve atresia and stenosis	327	161	77	16	11	592	
	9.9	***11.2***	***8.5***	***6.2***	***13.7***	***9.8***	
Pulmonary valve atresia	48	36	16	1	2	103	
	1.4	***2.5***	***1.8***	***0.4***	***2.5***	***1.7***	
Rectal and large intestinal atresia/stenosis	136	52	33	12	3	237	
	4.1	***3.6***	***3.6***	***4.6***	***3.7***	***3.9***	
Renal agenesis/hypoplasia	203	85	50	12	4	360	
	6.1	***5.9***	***5.5***	***4.6***	***5.0***	***6.0***	
Single ventricle	13	13	7	2	0	36	
	0.4	***0.9***	***0.8***	***0.8***	***0.0***	***0.6***	
Small intestinal atresia/stenosis	98	44	36	5	6	189	
	3.0	***3.1***	***4.0***	***1.9***	***7.5***	***3.1***	
Spina bifida without anencephalus	121	39	33	7	1	206	
	3.7	***2.7***	***3.6***	***2.7***	***1.2***	***3.4***	
Tetralogy of Fallot	156	92	37	11	3	302	
	4.7	***6.4***	***4.1***	***4.3***	***3.7***	***5.0***	
Total anomalous pulmonary venous connection	29	16	18	4	1	69	
	0.9	***1.1***	***2.0***	***1.5***	***1.2***	***1.1***	
Transposition of the great arteries (TGA)	118	41	20	3	1	186	
	3.6	***2.9***	***2.2***	***1.2***	***1.2***	***3.1***	
Dextro-transposition of great arteries (d-TGA)	106	36	15	3	1	164	
	3.2	***2.5***	***1.6***	***1.2***	***1.2***	***2.7***	
Tricuspid valve atresia and stenosis	78	36	22	4	3	144	
	2.4	***2.5***	***2.4***	***1.5***	***3.7***	***2.4***	
Tricuspid valve atresia	63	31	20	4	3	122	
	1.9	***2.2***	***2.2***	***1.5***	***3.7***	***2.0***	
Trisomy 13	23	27	18	2	1	80	
	0.7	***1.9***	***2.0***	***0.8***	***1.2***	***1.3***	
Trisomy 18	82	36	33	5	2	180	
	2.5	***2.5***	***3.6***	***1.9***	***2.5***	***3.0***	
Trisomy 21 (Down syndrome)	376	161	211	26	15	837	
	11.4	***11.2***	***23.2***	***10.1***	***18.7***	***13.9***	
Turner syndrome	44	11	7	1	2	80	3
	2.7	***1.6***	***1.6***	***0.8***	***5.1***	***2.7***	
Ventricular septal defect	1,670	671	562	113	43	3,072	
	50.4	***46.7***	***61.7***	***43.7***	***53.6***	***51.1***	
Total live births	**331,167**	**143,783**	**91,038**	**25,854**	**8,018**	**601,595**	**4**
Male live births	**170,176**	**73,013**	**46,230**	**13,289**	**4,114**	**307,686**	
Female live births	**160,991**	**70,761**	**44,808**	**12,565**	**3,904**	**293,900**	

North Carolina

Birth Defects Counts and Prevalence 2014 - 2018 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	250	8	258	
	4.9	***0.9***	***4.3***	
Trisomy 13	48	30	80	
	0.9	***3.3***	***1.3***	
Trisomy 18	95	81	180	
	1.9	***8.8***	***3.0***	
Trisomy 21 (Down syndrome)	380	449	837	
	7.5	***48.8***	***13.9***	
Total live births	**509,601**	**91,981**	**601,595**	**4**

Notes

1. Data for this condition include persistent cloaca.
2. Data for this condition include male and unknown gender cases only. Prevalence is calculated per 10,000 male live births.
3. Data for this condition include female and unknown gender cases only. Prevalance is calculated per 10,000 female live births.
4. Data for total live births include unknown gender.

General comments

*Data for totals include unknown and/or other.
-Data for conditions exclude probable/possible cases.