

**CHAPTER 20**  
**BIRTH DEFECTS REGISTRY**

**Authority**

N.J.S.A. 26:80-40.20 et seq., specifically 26:80-40.21.

**Source and Effective Date**

R.2005 d.147, effective April 15, 2005.  
See: 36 N.J.R. 4357(a), 37 N.J.R. 1727(a).

**Chapter Expiration Date**

Pursuant to Executive Order No. 1(2010), the chapter expiration date is extended from April 15, 2010 until the completion of the review of administrative regulations and rules by the Red Tape Review Group, and until such time as the extended regulation or rule is readopted pursuant to the Administrative Procedure Act, N.J.S.A. 52:14B-1 et seq. See: 42 N.J.R. 1286(a).

**Chapter Historical Note**

Chapter 20, Birth Defects Registry, was adopted as R.1985 d.92, effective March 4, 1985. See: 16 N.J.R. 3118(a), 17 N.J.R. 591(a).

Pursuant to Executive Order No. 66(1978), Chapter 20, Birth Defects Registry, was readopted as R.1990 d.187, effective March 2, 1990. See: 21 N.J.R. 3636(a), 22 N.J.R. 1134(c).

Pursuant to Executive Order No. 66(1978), Chapter 20, Birth Defects Registry, was readopted as R.1995 d.182, effective March 2, 1995. See: 27 N.J.R. 269(a), 27 N.J.R. 1410(b).

Pursuant to Executive Order No. 66(1978), Chapter 20, Birth Defects Registry, was readopted as R.2000 d.99, effective February 10, 2000. See: 31 N.J.R. 2863(a), 32 N.J.R. 802(a).

Chapter 20, Birth Defects Registry, was readopted as R.2005 d.147, effective April 15, 2005. See: Source and Effective Date. See, also, section annotations.

Subchapter 2, Autism, was adopted as new rules by R.2009 d.281, effective September 21, 2009. See: 40 N.J.R. 6514(a), 41 N.J.R. 3416(a).

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**SUBCHAPTER 1. LIVE BIRTHS**

**8:20-1.1 Definitions**

The following words and terms when used in this chapter shall have the following meanings unless the context clearly indicates otherwise.

“Bilirubin” means the orange-yellow pigment found in bile, which is formed when hemoglobin, the red-colored pig-

ment of red blood cells that carries oxygen to tissues, breaks down into heme and globin.

“Birth defect” means an abnormality of the body’s structure or inherent function which is present at birth, whether such abnormality is manifest at the time of delivery or becomes apparent later in life.

“Child” means an individual from birth through five years of age.

“Clinical laboratory” shall have the meaning given in the New Jersey Clinical Laboratory Improvement Act, N.J.S.A. 45:9-42.26 et seq.

“Commissioner” means the Commissioner of the New Jersey Department of Health and Senior Services.

“Department” means the New Jersey Department of Health and Senior Services.

“Direct or conjugated bilirubin” means the substance that is produced when heme is converted to bilirubin, which is then carried by albumin in the blood to the liver. In the liver, the bilirubin is chemically attached or conjugated to another molecule before it is released in the bile.

“Exchange transfusion” means a simultaneous withdrawal of the newborn’s blood and transfusion with the donor’s blood.

“Fractionated bilirubin” means the total and direct bilirubin with the calculation of indirect bilirubin.

“Health care professional” means a physician, dentist, certified nurse midwife or other health care professional licensed pursuant to Title 45 of the Revised Statutes.

“Indirect or unconjugated bilirubin” means the unconjugated, lipid-soluble form of bilirubin that circulates in loose association with the plasma proteins.

“International Classification of Diseases, Ninth Revision, Clinical Modification” or “ICD-9-CM” means the document published by the World Health Organization, which promotes the international comparability in the collection, processing, classification, and presentation of mortality statistics, and which is incorporated herein by reference, as amended and supplemented. The ICD-9-CM is available for download at the National Center for Health Statistics’ webpage at [http://www.cdc.gov/nchs/products/elec\\_prods/subject/icd96ed.htm](http://www.cdc.gov/nchs/products/elec_prods/subject/icd96ed.htm).

“Kernicterus” means a condition marked by the deposit of bile pigments in the nuclei of the brain and spinal cord and by degeneration of nerve cells.

“Newborn” means an infant from birth up to and including 30 days of age.

“Total serum bilirubin” means direct bilirubin plus indirect bilirubin.

“Transcutaneous bilirubin measurement” means a procedure that measures the total serum bilirubin in newborns without a blood sample.

Amended by R.2005 d.147, effective May 16, 2005.

See: 36 N.J.R. 4357(a), 37 N.J.R. 1727(a).

In “Infant”, substituted “through” for “to” preceding “one year of age”.

Amended by R.2009 d.281, effective September 21, 2009.

See: 40 N.J.R. 6514(a), 41 N.J.R. 3416(a).

In the introductory paragraph, substituted “chapter” for “document”; added definitions “Bilirubin”, “Clinical laboratory”, “Commissioner”, “Department”, “Direct or conjugated bilirubin”, “Exchange transfusion”, “Fractionated bilirubin”, “Health care professional”, “Indirect or unconjugated bilirubin”, “International Classification of Diseases, Ninth Revision, Clinical Modification”, “Kernicterus”, “Newborn”, “Total serum bilirubin” and “Transcutaneous bilirubin measurement”; substituted definition “Child” for definition “Infant”; and rewrote definition “Child”.

### 8:20-1.2 Reporting requirements

(a) A health care professional shall report any child who is born to a resident of the State of New Jersey, or who becomes a resident of the State prior to and through five years of age, and who is diagnosed as having a defect either at birth or any time through the fifth year of life to the Department, Special Child Health and Early Intervention Services Program as follows:

1. The conditions listed as Congenital Anomalies (Diagnostic Codes 740.00 through 759.90) in the most recent revision of the International Classification of Diseases, Clinical Modification (ICD-9-CM), shall, except as specified in (a)1ii below, be reported to Special Child Health and Early Intervention Services. In addition, there are several other conditions considered to be birth defects that are not listed under Diagnostic Codes 740.00 through 759.90, which describe Congenital Anomalies. The birth defects listed in (a)1i below shall also, in every case, be reported to Special Child Health and Early Intervention Services. The minor conditions listed in (a)1ii below shall not be reported to Special Child Health and Early Intervention Services in every case, but only as required in (a)1iii, iv and v below.

i. Congenital anomalies include, but are not limited to, the following:

- (1) Anencephalus and similar anomalies, such as craniorachischis and inencephaly;
- (2) Spina bifida with and without mention of hydrocephalus;
- (3) Other congenital anomalies of the nervous system, such as: encephalocele; microcephalus; reduction deformities of the brain; congenital hydrocephalus; congenital cerebral palsies, congenital muscular dystrophies; and other anomalies, congenital diseases, lesions and any other deformities of the brain, nervous system or spinal cord;
- (4) Congenital anomalies of the eye, such as: anophthalmos; microphthalmos; buphthalmos; cong-

enital cataract and lens anomalies; coloboma and other anomalies of the anterior or posterior segment; congenital anomalies of eyelids, lacrimal system and orbit; and any other anomalies of the eye;

(5) Congenital anomalies of the ear, face and neck, such as: anomalies of the ear causing impairment of hearing; any other anomalies of the ear; branchial cleft cyst or fistula; and any other anomalies of face and neck;

(6) Bulbus cordis anomalies and anomalies of cardiac septal closure, such as: common truncus; transposition of great vessels; Tetralogy of Fallot; common ventricle; ventricular septal defect; ostium secundum type atrial septal defect; endocardial cushion defects; cor biloculare; and any other defects of septal closure;

(7) Other congenital anomalies of the heart, such as: anomalies of pulmonary valve; congenital tricuspid atresia and stenosis; Ebstein’s anomaly; congenital stenosis of aortic valve; congenital mitral stenosis of aortic valve; congenital mitral stenosis or insufficiency; hypoplastic left heart syndrome; and any other structural anomalies of the heart;

(8) Other congenital anomalies of circulatory system, such as: patent ductus arteriosus (only in children, if greater than 36 weeks gestation, and defect noted at greater than six weeks of age); coarctation of aorta and other anomalies of the aorta, aortic arch or atresia and stenosis of the aorta; anomalies of pulmonary artery; anomalies of great veins; other anomalies of peripheral vascular system; or other unspecified anomalies of circulatory system;

(9) Congenital anomalies of respiratory system, such as: choanal atresia; other anomalies of nose; webbing of larynx; other anomalies of larynx, trachea and bronchus; congenital cystic lung; agenesis, hypoplasia and dysplasia of lung; other anomalies of the lung; and other unspecified anomalies of respiratory system;

(10) Cleft palate and cleft lip;

(11) Other congenital anomalies of upper alimentary tract, such as: anomalies of the tongue; anomalies of mouth and pharynx; tracheoesophageal fistula, esophageal atresia, and stenosis and other anomalies of esophagus; congenital hypertrophic pyloric stenosis, congenital hiatal hernia; other anomalies of stomach; and other unspecified anomalies of upper alimentary tract;

(12) Other congenital anomalies of digestive system, such as: atresia and stenosis of small intestine, large intestine, rectum and anal canal; Hirschsprung’s disease and other congenital functional disorders of colon; anomalies of intestinal fixation; other anomalies of intestine, gall bladder, bile ducts, liver and