1 of 7 DOCUMENTS

NEW JERSEY ADMINISTRATIVE CODE

*** This file includes all Regulations adopted and published through the ***
*** New Jersey Register, Vol. 43, No. 20, October 17, 2011 ***

TITLE 8. HEALTH AND SENIOR SERVICES
CHAPTER 20. BIRTH DEFECTS REGISTRY

N.J.A.C. 8:20 (2011)

Title 8, Chapter 20 -- Chapter Notes

CHAPTER AUTHORITY:

N.J.S.A. 26:2-103.9, 26:2-185 et seq., and *26:8-40.26*.

CHAPTER SOURCE AND EFFECTIVE DATE:

R.2010 d.268, effective October 20, 2010.

See: *42 N.J.R. 1286(a), 42 N.J.R. 2806(a)*.

CHAPTER EXPIRATION DATE:

In accordance with N.J.S.A. 52:14B-5.1b, Chapter 20, Birth Defects Registry, expires on October 20, 2017. See: *43 N.J.R. 1203(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: *36 N.J.R. 4357(a), 37 N.J.R. 1727(a)*.

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).*

Pursuant to Executive Order No. 1(2010), the chapter expiration date was 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 was readopted pursuant to the Administrative Procedure Act, *N.J.S.A. 52:14B-1* et seq. See: *42 N.J.R. 1286(a).*

Chapter 20, Birth Defects Registry, was readopted as R.2010 d.268, effective October 20, 2010. See: Source and Effective Date.

NOTES:
Chapter Notes

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TITLE 8. HEALTH AND SENIOR SERVICES
CHAPTER 20. BIRTH DEFECTS REGISTRY
SUBCHAPTER 1. LIVE BIRTHS

N.J.A.C. 8:20-1.1 (2011)

§ 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 pigment 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.

"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.

HISTORY:

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".

NOTES:
Chapter Notes

3 of 7 DOCUMENTS

NEW JERSEY ADMINISTRATIVE CODE

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TITLE 8. HEALTH AND SENIOR SERVICES
CHAPTER 20. BIRTH DEFECTS REGISTRY
SUBCHAPTER 1. LIVE BIRTHS

N.J.A.C. 8:20-1.2 (2011)

§ 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; congenital 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 pancreas; disorders of tooth formation, development and eruption, dentofacial anomalies and other unspecified anomalies of the digestive system;

(13) Congenital anomalies of genital organs, such as: anomalies of ovaries, fallopian tubes and broad ligaments; doubling of uterus and other anomalies of uterus; anomalies of cervix, vagina and external female genitalia; hypospadias and congenital chordee; indeterminate sex and pseudohermaphroditism; and other unspecified anomalies of the genital system;

(14) Congenital anomalies of urinary system, such as: renal agenesis and dysgenesis; cystic kidney disease; obstructive defects of renal pelvis and ureter; other anomalies of kidney and ureter; exstrophy of urinary bladder; atresia and stenosis of urethra and bladder neck; anomalies of urachus; other anomalies of bladder and urethra; and other unspecified anomalies of the urinary system;

(15) Certain congenital musculoskeletal deformities, such as: of skull, face and jaw; of sternocleidomastoid muscle; of spine; congenital dislocation of hip; congenital genu recurvatum and bowing of long bones of leg; varus and valgus deformities of feet; other congenital deformities of feet, such as talipes cavus, calcaneus or equinus; and other specified nonteratogenic anomalies, such as pectus excavatum, pectus carinatum; club hand; congenital deformity of chest wall; generalized flexion contractures of lower limbs; or spade-like hand;

(16) Other congenital anomalies of limbs, such as: syndactyly when fingers are joined by tissue and/or bone to distal tips; reduction deformities of upper limb; reduction deformities of lower limb; other anomalies of upper limb, including shoulder girdle; and other anomalies of lower limb, including pelvic girdle;

(17) Other congenital musculoskeletal anomalies, such as: anomalies of skull and facial bones; anomalies of spine; cervical rib; other anomalies of ribs and sternum; chondrodystrophy; osteodystrophies; anomalies of diaphragm; anomalies of abdominal wall, such as prune belly syndrome; other specified anomalies of muscle, tendon, fascia and connective tissue; and other unspecified anomalies of musculoskeletal system;

(18) Congenital anomalies of the integument, significant anomalies of skin, subcutaneous tissue, hair, nails and breast, such as birthmarks or nevi measuring four inches or greater in size, multiple skin tags (more than five in number);

(19) Chromosomal anomalies, such as: Down syndrome; Patau syndrome; Edwards syndrome; autosomal deletion syndromes and other conditions due to autosomal anomalies; gonadal dysgenesis; Klinefelter syndrome; and other conditions due to sex chromosome anomalies or anomalies of unspecified chromosome;

(20) Other and unspecified congenital anomalies, such as: anomalies of spleen, situs inversus; conjoined twins; tuberous sclerosis; other hamartoses; multiple congenital anomalies; and other congenital anomalies, including congenital malformation syndromes affecting multiple organ systems, including Laurence-Moon-Biedl syndrome, Marfan syndrome and Prader-Willi syndrome;

(21) Certain endocrine, nutritional and metabolic diseases and immunity disorders, including congenital hypothyroidism; congenital hypoparathyroidism; hypopituitarism; diencephalic syndrome; adrenogenital syndrome; testicular

feminization syndrome; phenylketonuria; albinism; maple syrup urine disease; argininosuccinic aciduria; glycogen storage diseases; cystic fibrosis; alpha-1 antitrypsin deficiency; DiGeorge syndrome; congenital deficiencies of humoral immunity; cell-mediated immunity; combined immunity deficiencies; and other specified and unspecified disorders of the immune mechanisms;

(22) Certain diseases of the blood and blood-forming organs, including hemolytic diseases of the newborn; G-6PD deficiency; hemophilia (all types); Von Willebrand disease; and sickle-cell anemias or other hemoglobinopathies;

(23) Certain diseases of the nervous system and sense organs, including hereditary and degenerative diseases of the central nervous system, such as Tay-Sachs disease and familial degenerative Central Nervous System (CNS) diseases; Werdnig-Hoffmann disease; cerebral palsy; Moebius syndrome; hereditary retinal dystrophies and chorioretinitis;

(24) Certain diseases of the circulatory system, including endocardial fibroelastosis; congenital Wolfe-Parkinson-White syndrome and Budd-Chiari syndrome;

(25) Certain diseases of the digestive system, including abnormalities of jaw size, micrognathia and macrognathia; congenital inguinal hernia with gangrene (only in females), congenital inguinal hernia with obstruction with no mention of gangrene (only in females); congenital inguinal hernia without obstruction with no mention of gangrene (only in females), umbilical hernia (only if not covered by skin), epigastric hernia;

(26) Certain complications of pregnancy, childbirth and the puerperium, including amniotic bands;

(27) Certain diseases of the skin and subcutaneous tissue; pilonidal sinus;

(28) Certain conditions originating in the perinatal period, including fetal alcohol syndrome, probable fetal alcohol syndrome (includes facies), fetal alcohol effects, fetal hydantoin (Dilantin) syndrome, unspecified TORCH infection and certain congenital infections, including congenital syphilis, congenital rubella, cytomegalovirus, toxoplasmosis, hepatitis and herpes simplex; and

(29) Neoplasms, including lipomas of skin and subcutaneous tissue of face and other skin and subcutaneous tissue, intrathoracic and intra-abdominal organs, spermatic cord, other specified sites, lumbar, sacral, paraspinal, and other unspecified sites; benign neoplasms of skin, including blue nevus, pigmented nevus (include if greater than four inches in diameter), papilloma, dermatofibroma, syringoadenoma, dermoid cyst, hydrocystoma, syringoma; other benign neoplasms of lip, eyelid, ear, external auditory canal, skin and other unspecified parts of face, scalp, skin of neck, skin of trunk, skin of upper limb, skin of lower limb, other specified and unspecified sites, including hairy nevus; hemangioma (include if: greater than four inches in diameter, multiple, more than five in number or cavernous hemangioma) of skin and subcutaneous tissue, intracranial, intra-abdominal cystic hygroma; lymphangioma of any site, hemangioma of other and unspecified site; and certain malignant neoplasms, including Wilm's tumor, retinoblastoma, other congenital neoplasms, including neuroblastoma, medulloblastoma, teratoma, fibrosarcoma, histiocytosis (malignant) and neurofibromatosis.

ii. Minor conditions are as follows:

(1) Accessory auricle;

(2) Accessory nipple (supernumerary nipple or skin tag);

(3) Amniotic bands (constricting bands)--except when cause of loss of body parts, amniotic cysts;

(4) Anal fissure--never a defect;

(5) Anal tags;

(6) Aortic valve insufficiency or regurgitation, congenital--register cases designated as 'mild,' 'minimal,' 'trivial' or 'physiologic' only if another reportable defect is present;

(7) Ascites or anasarca, congenital, includes hydrops fetalis;

(8) Bat ear;

(9) Bell's Palsy;

(10) Bent nose, deviation of nasal septum;

(11) Big lips;

(12) Blue sclera (babies less than 2,500 grams);

(13) Brachial palsy;

(14) Breast Hypertrophy--never a defect;

(15) Bronchopulmonary dysplasia (Wilson-Mikity syndrome);

(16) Brushfield spots;

(17) Cafe-au-lait spots (register if five or more);

(18) Caput succedaneum;

(19) Cardiac murmur--do not register innocent or functional murmurs: register only if there is a definitive cardiac anomaly or register as a rule out condition if the cause of murmur is not identified at the time of discharge;

(20) Cardiomegaly, congenital--Not Otherwise Specified (NOS);

(21) Cauliflower ear;

(22) Central nervous system (CNS) hemorrhage;

(23) Cephalhematoma--never a defect;

(24) Cervical rib;

(25) Chylothorax and other specified disorders of the lymphatics;

(26) Clinodactyly (incurving of fifth finger);

(27) Congenital hydrocele;

(28) Conjunctivitis--never a defect;

(29) Cryptorchidism (undescended testicle)--register only if there is clinical evidence of congenital absence;

(30) Darwin's tubercle;

(31) Diastasis recti--never a defect;

(32) Dolicocephaly--if less than 36 weeks gestation - always register if greater than 36 weeks;

(33) Downward eyeslant (antimongoloid);

(34) Ear tags, preauricular tags, or other ear tags;

(35) Elfin ear--absent or decreased ear cartilage if less than 36 weeks gestation;

(36) Epicanthal folds;

(37) Epulis--never a defect;

(38) Erb's palsy;

(39) Erythema toxicum;

(40) Esotropia;

(41) Exotropia;

(42) Facial palsy;

(43) Flammeus nevus or port wine stain (less than four inches in diameter);

(44) Flat bridge or nose;

(45) Fontanel (large or small);

(46) Fractured clavicle;

(47) Fused eyelids (not a defect if birth weight is less than 1,001 grams);

(48) Fusion of vulva;

(49) Gastroesophageal reflux--never a defect;

(50) Hemangioma--less than four inches in diameter; Register cavernous hemangiomas and multiples of five or more;

(51) Hepatomegaly;

(52) High arched palate;

(53) Hipclick--without follow-up or therapy--never a defect;

(54) Hyaline membrane disease;

(55) Hydrocephaly; acquired--secondary to intraventricular hemorrhage (IVH) or CNS bleed;

(56) Hymenal tags;

(57) Hyperglycemia;

(58) Hypoglycemia, idiopathic;

(59) Hypophosphatemic rickets;

(60) Hypoplasia of lung; pulmonary hypoplasia--exclude only if an isolated defect in infants less than 36 weeks gestation;

(61) Hypoplastic labia majora--if less than 36 weeks gestation - always report if greater than 36 weeks gestation;

(62) Hypoplastic scrotum--exclude if secondary to undescended testes;

(63) Imperforate hymen;

(64) Inguinal hernia or patent processus vaginalis. Never a defect in infants less than 36 weeks gestation. For infants greater than 36 weeks gestation: males, never report; females, always report;

(65) Infant of a diabetic mother; asymptomatic;

(66) Intestinal obstruction--requires chart review to determine if cause of obstruction is a registerable defect. If so, register only the cause;

(67) Intussusception--requires chart review to determine if cause of intussusception is a reportable defect. If so, register only the cause;

(68) Inverted nipples;

(69) Lanugo, excessive or persistent;

(70) Laryngomalacia or tracheomalacia--never a defect;

(71) Long fingers and/or toes;

(72) Lop ear;

(73) Low set ears;

(74) Meckel's diverticulum;

(75) Meconium peritonitis;

(76) Meconium plug;

(77) Meconium-stained skin or nails--never a defect;

(78) Metatarsus adductus--never a defect;

(79) Metatarsus varus;

(80) Mitral valve insufficiency or regurgitation, congenital. Register cases designated as mild, minimal or trivial or physiologic only if another registerable defect is present;

(81) Mongolian spots;

(82) Mucocele--never a defect;

(83) Nasal lacrimal duct obstruction;

(84) Nail defects;

(85) Natal teeth;

(86) Nystagmus;

(87) Occiput flat or prominent;

(88) Orthopedic positional anomalies--do not register if defect can be corrected passively and does not require casting or bracing;

(89) Overlapping toes;

(90) Overriding (overlapping) sutures--never a defect;

(91) Patent ductus arteriosus (PDA):

(A) Always register if greater than 36 weeks gestation and defect last noted at greater than six weeks of age;

(B) If greater than 36 weeks gestation and defect last noted at less than six weeks of age, register only if the PDA was treated (for example, by ligation or indomethacin) or if another registerable defect is present; and

(C) Never register if less than 36 weeks gestation or if treated with prostaglandins regardless of gestational age;

(92) Patent foramen ovale (PFO):

(A) Never register a child with a PFO unless the PFO is greater than four millimeters in diameter at any time; and

(B) If an echocardiogram is done but the PFO defect size is not stated, do not register;

(93) Patent urachus;

(94) Patulous lips (wide lips);

(95) Peripheral pulmonic stenosis (PPS)--murmur--do collect if PPS documented by echocardiogram;

(96) Persistent pulmonary hypertension in the newborn;

(97) Petechiae--never a defect;

(98) Phimosis--never a defect;

(99) Pilonidal and sacral dimple;

(100) Pilonidal cyst;

(101) Pixie-like ear;

(102) Pneumothorax;

(103) Pointed ear;

(104) Polydactyly in blacks or African Americans (postaxial, type B)--includes only skin tags on hands or feet. All other types of postaxial polydactyly, for example, having an extra finger with bone and/or nail, should always be registered;

(105) Posteriorly rotated ears;

(106) Preauricular sinus, cyst or pit;

(107) Premature atrial contractions;

(108) Prominent clitoris;

(109) Protruding tongue;

(110) Pulmonary valve insufficiency or regurgitation, congenital - register cases designated as mild, minimal, trivial or physiologic only if another registerable defect is present;

(111) Pylorospasm (intermittent pyloric stenosis);

(112) Ranula--never a defect;

(113) Rectal fissure;

(114) Redundant foreskin;

(115) Redundant neck skin folds;

(116) Retractile testes;

(117) Rockerbottom feet;

(118) Scaphocephaly, no mention of craniosynostosis--always register if greater than 36 weeks gestation (acquired or positional never a defect);

(119) Sebaceous cysts;

(120) Short neck;

(121) Simian crease (transverse palmar crease);

(122) Single umbilical artery;

(123) Skin cysts or tags;

(124) Small lips (microcheilia);

(125) Small nipple (hypoplastic)--always register if greater than 36 weeks gestation;

(126) Splenomegaly;

(127) Thymic hypertrophy;

(128) Tibial torsion;

(129) Tongue-tie;

(130) Torsion of spermatic cord;

(131) Torsion of testes;

(132) Tracheomalacia--never a defect;

(133) Tricuspid valve insufficiency or regurgitation--congenital--register cases designated as mild, minimal, trivial or physiologic only if another registrable defect is present;

(134) Umbilical cord atrophy;

(135) Umbilical hernias (completely covered by skin);

(136) Upturned nose;

(137) Upward eyeslant (mongoloid);

(138) Vaginal cysts;

(139) Vaginal tags;

(140) Volvulus - requires chart review to determine if cause of volvulus is a registrable defect. If so, register only the cause;

(141) Webbed toes (syndactyly)--register webbing of the second and third toes only if another reportable defect is present. Always register webbing of other toes regardless of whether another reportable defect is present;

(142) Webbing of neck;

(143) Wide nasal bridge;

(144) Widely spaced nipples; and

(145) Widely spaced first and second toes.

iii. If a condition or defect listed in (a)1ii above appears as a single defect, a registration form shall not be completed.

iv. If two or more of the conditions listed in (a)1ii above appear, a registration form shall be completed.

v. If a condition or defect listed in (a)1ii above accompanies a condition or defect listed in either Diagnostic Codes 740.00 through 759.90 in the most recent revision of the International Classification of Diseases, Clinical Modification, or in (a)1i above, a registration form shall be completed.

(b) Clinical laboratories shall report to the Department any newborn who is a resident of the State of New Jersey, regardless of gestational age, who has a total serum bilirubin (TSB) of 25 milligrams per deciliter (mg/dl) or greater, or who receives an exchange transfusion. For reporting purposes, transcutaneous bilirubin measurements, without validation by TSB laboratory analysis, shall not be accepted.

1. Clinical laboratory directors shall report to the Department the results of all TSB, fractionated when available, having levels 25 mg/dl or greater, in newborns.

2. Clinical laboratory directors shall submit the report by the fifth day of each month which shall contain the results of all TSB specimens from newborns having levels of 25 mg/dl or greater that have been analyzed during the previous month.

3. Clinical laboratories shall report only one TSB, 25 mg/dl or greater, test result per child.

4. The clinical laboratory director shall send the report to the New Jersey Birth Defects Registry in the manner prescribed in (g) below to the Registry website address at: www.nj.gov/health/fhs/sch/schr.shtml.

5. The report shall contain the results of the laboratory examination units; type of specimen tested; date and time the sample was collected; date and time the sample was analyzed; name of the newborn; address of the newborn; date of birth of the newborn; medical record number; name and phone number of the requesting physician; name, address, and telephone number of the laboratory performing the test; and the name of newborn's parent/guardian or insured party.

(c) Any live born child with a birth defect who has not been previously registered and has expired shall be reported. Such reports shall indicate that the child has expired.

(d) The administrative officer of every health care facility shall be responsible for establishing the reporting procedures for that facility. The reporting procedures must insure that every infant who has a birth defect shall be reported to the Department. All presumptive, tentative, pending or rule out diagnoses will be reported at the time of discharge, if the child will be diagnosed at a later time or if test results are pending.

(e) Every health care professional who treats, manages or who has any medical responsibility for, diagnoses or confirms birth defects shall report to the Department each child diagnosed as having a birth defect not known to be previously reported.

(f) The director of every clinical laboratory shall report to the Department results of a postmortem examination from any child, indicating the existence of a birth defect, not known to be previously reported.

(g) The reports required by this section shall be sent to the Department on the SCH-O form available on the Registry website at http://www.state.nj.us/health/fhs/sch/schr.shtml, either electronically, as described on the website, or by mail to the following address:

Special Child Health and Early Intervention Services
Early Identification and Monitoring/Birth Defects Registry
PO Box 364
Trenton, New Jersey 08625-0364

(h) The reports made pursuant to these rules are to be used only by the Department and other agencies that may be designated by the Commissioner and shall not otherwise be divulged or made public, so as to disclose the identity of any person; and such reports shall not be included under materials available to public inspection pursuant to the "Open Public Records Act," *N.J.S.A. 47:1A-1* et seq.

(i) Cytogenetic laboratories shall report the results of all postnatal chromosomal abnormalities.

(j) When a child is registered, the Department shall inform the parent or legal guardian of the registration.

(k) Every health care facility and independent clinical laboratory shall allow access to or provide necessary information on children with birth defects and other patients specified by characteristics for research studies related to birth defects conducted by the Department and which have been approved by the Commissioner after appropriate review for assuring protection of human subjects by the Department's Institutional Review Board. This shall include patients who came under the care of the health facility prior to March 4, 1985.

(*l*) Any agency designated by the Commissioner to receive reports pursuant to this subchapter shall provide to Special Child Health and Early Intervention Services any updated diagnostic and/or demographic information.

HISTORY:

Amended by R.1987 d.361, effective September 8, 1987.

See: 19 N.J.R. 909(b), 19 N.J.R. 1642(b).

Subsection (a) added a list of congenital anomalies and other conditions which also constituted reportable birth defects.

Amended by R.1990 d.187, effective April 2, 1990.

See: 21 N.J.R. 3636(a), 22 N.J.R. 1134(c).

Reporting requirements for certain conditions specified further; reporting requirements for sickle-cell anemia and other hemoglobinopathies added; all presumptive, tentative, pending and rule out diagnoses to be reported at discharge; cytogenic laboratories to report postnatal chromosomal abnormality test results to the Department.

Amended by R.1991 d.414, effective August 5, 1991.

See: 23 N.J.R. 820(a), 23 N.J.R. 2335(a).

In (a)1, added ii. through v.

Amended by R.1992 d.184, effective April 20, 1992.

See: 24 N.J.R. 171(a), 24 N.J.R. 1494(b).

Minor conditions added at (a)1ii.

Amended by R.2000 d.99, effective March 6, 2000.

See: *31 N.J.R. 2863(a), 32 N.J.R. 802(a)*.

In (a) and (f), substituted references to Special Child, Adult and Early Intervention Services for references to Special Child Health Services; rewrote (d); in (j), inserted a reference to the Department's Institutional Review Board at the end of the first sentence, and substituted a reference to March 4, 1985 for a reference to the effective date of the regulations at the end of the last sentence; and added (k).

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

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

In (a), substituted "prior to and through" for "before" preceding "one year of age" and substituted "through" for "during" preceding "the first year of life" in the introductory paragraph.

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

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

Rewrote the section.

NOTES:
Chapter Notes

4 of 7 DOCUMENTS

NEW JERSEY ADMINISTRATIVE CODE

*** This file includes all Regulations adopted and published through the ***
*** New Jersey Register, Vol. 43, No. 20, October 17, 2011 ***

TITLE 8. HEALTH AND SENIOR SERVICES
CHAPTER 20. BIRTH DEFECTS REGISTRY
SUBCHAPTER 1. LIVE BIRTHS

N.J.A.C. 8:20-1.3 (2011)

§ 8:20-1.3 Reporting requirements for hearing loss

Physicians and audiologists shall complete and file a Special Health Services Registration form for any child from birth through 21 years of age diagnosed with any permanent hearing loss, as required by *N.J.A.C. 8:19-1.11*.

HISTORY:

New Rule, R.2009 d.281, effective September 21, 2009.

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

NOTES:
Chapter Notes

5 of 7 DOCUMENTS

NEW JERSEY ADMINISTRATIVE CODE

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*** New Jersey Register, Vol. 43, No. 20, October 17, 2011 ***

TITLE 8. HEALTH AND SENIOR SERVICES
CHAPTER 20. BIRTH DEFECTS REGISTRY
SUBCHAPTER 2. AUTISM

N.J.A.C. 8:20-2.1 (2011)

§ 8:20-2.1 Purpose and scope

This subchapter is intended to implement the requirements of P.L. 2007, c. 170 (*N.J.S.A. 26:2-185* et seq.) by providing for the reporting of diagnoses of autism and for the creation and maintenance of an up-to-date Autism Registry of all reported cases of autism that occur in New Jersey for use in conducting thorough and complete epidemiologic surveys of autism.

NOTES:
Chapter Notes

6 of 7 DOCUMENTS

NEW JERSEY ADMINISTRATIVE CODE

*** This file includes all Regulations adopted and published through the ***
*** New Jersey Register, Vol. 43, No. 20, October 17, 2011 ***

TITLE 8. HEALTH AND SENIOR SERVICES
CHAPTER 20. BIRTH DEFECTS REGISTRY
SUBCHAPTER 2. AUTISM

N.J.A.C. 8:20-2.2 (2011)

§ 8:20-2.2 Definitions

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

"Asperger Syndrome" means a disorder defined by DSM criteria (criteria 299.80) and marked by clinically significant impairments in social interaction and the presence of restricted, repetitive and stereotyped patterns of behavior, interests and activities. There are no clinically significant delays in the development of language, cognition, self-help skills or adaptive behavior. These criteria are not met for another specific pervasive developmental disorder.

"Autism" means a developmental disability as defined by DSM criteria, and diagnosed according to standard DSM criteria, which is marked by significant impairments in social interaction and communication and the presence of unusual behaviors and interests. Autism includes the following diagnoses commonly known as the Autism Spectrum Disorders: Asperger Syndrome; Autistic Disorder; and Pervasive Developmental Disorder Not otherwise Specified; and the Pervasive Developmental Disorders, including Rett Syndrome and Childhood Disintegrative Disorder, the causes of which are currently not known.

"Autistic disorder" means a disorder defined by DSM criteria (criteria 299.00) and marked by qualitative impairments in social interaction and communication and the presence of repetitive and stereotyped patterns of behavior with onset prior to three years of age and that is not better accounted for by Rett Syndrome or Childhood Disintegrative Disorder.

"Child" means an individual from birth through 21 years of age.

"Childhood Disintegrative Disorder" means a disorder as defined by DSM criteria (criteria 299.10) and that appears after at least two years of normal development after birth and results in the clinically significant loss of previously acquired skills in at least two areas of functioning (language, social skills, adaptive behavior, bowel/bladder control, play or motor skills) before age 10. There are abnormalities of functioning in social interaction, communication and the presence of restricted and stereotyped patterns of behavior and is not better accounted for by another pervasive developmental disorder or by schizophrenia.

"Custodian" means a person, financial institution or agency that has charge or custody of property, securities, papers and other such assets of an individual.

"DSM criteria" means the professional standard behavioral criteria for autism published in the American Psychiatric Association: Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) (criteria 299.0 - 299.90), Washington DC, American Psychiatric Association, 2000, which is incorporated herein by reference, as amended and supplemented. Copies of DSM-IV may be obtained from the American Psychiatric Association, 1400 K Street, N.W., Washington, D.C., 20005.

"Health care professional" means a physician, psychologist and any other health care professional licensed pursuant to Title 45 of the Revised Statutes and who is qualified by training to make a diagnosis of autism.

"Legal guardian" means a person who has the legal authority to care for the personal and property interests of another person.

"Parent" means a biological parent, stepparent or adoptive parent.

"Pervasive Developmental Disorder Not Otherwise Specified" means a disorder defined by DSM criteria (criteria 299.80) and marked by severe and pervasive impairment in the development of social interaction or verbal and nonverbal communication or when stereotyped behavior, interests and activities are present but the criteria are not met for a specific pervasive developmental disorder. This category includes "atypical autism."

"Rett Syndrome" means a disorder defined by DSM criteria (criteria 299.80) and that appears after apparently normal prenatal and perinatal development and which results in severe impairment in expressive and receptive language, loss of social engagement, retardation of psychomotor development, loss of previously acquired purposeful hand skills and the development of stereotyped hand movements.

NOTES:
Chapter Notes

7 of 7 DOCUMENTS

NEW JERSEY ADMINISTRATIVE CODE

*** This file includes all Regulations adopted and published through the ***
*** New Jersey Register, Vol. 43, No. 20, October 17, 2011 ***

TITLE 8. HEALTH AND SENIOR SERVICES
CHAPTER 20. BIRTH DEFECTS REGISTRY
SUBCHAPTER 2. AUTISM

N.J.A.C. 8:20-2.3 (2011)

§ 8:20-2.3 Reporting requirements

(a) A health care professional shall report to the Department any person, from birth through 21 years of age, who is a resident of the State of New Jersey and is diagnosed with autism based on DSM criteria, and who is not known to be previously registered.

(b) The health care professional shall send the report required by (a) above to the Department on the SCH-0 form available on the Registry website at http://www.state.nj.us/health/fhs/sch/schr.shtml, either electronically, as described on the website, or by mail to the following address:

Special Child Health and Early Intervention Services
Early Identification and Monitoring/Autism Registry
PO Box 364
Trenton, New Jersey 08625-0364

(c) The administrative officer of every health care facility shall establish procedures for reporting to the Department the information required by (d) below for any person from birth through 21 years of age who is diagnosed with autism.

(d) The report shall be in writing on the SCH-O form and shall include the name, age, race/ethnicity, and address of the person with the diagnosis of autism, registration type, insurance information, child's birth information, diagnosis information, diagnostician's information and contact information for the person submitting the form.

(e) Pursuant to N.J.S.A. 26:2-188c, nothing in this act shall be construed to compel a child with the diagnosis of autism who has been reported to submit to medical or health examination or supervision by the Department.

(f) Every health care facility and independent clinical laboratory shall allow access to, or provide necessary information on persons with autism for any studies conducted by the Department after appropriate review for assuring protection of human subjects by the Department's Institutional Review Board.

(g) Any agency designated by the Commissioner to receive autism reports shall send to the Department, in the manner prescribed in (b) above, any updated diagnostic and/or demographic information in writing on the SCH-O form.

(h) A health care professional shall not report to the Department the personal identifying information of a child diagnosed with autism if the child's parent, legal guardian or custodian objects to the reporting and a health care professional shall not report to the Department the personal identifying information of an individual through age 21 diagnosed with autism, if the individual through age 21 objects to the reporting.

(i) At the time of diagnosis or prior to submitting the report required by (b) above, the health care professional shall inform the parent, legal guardian, custodian or individual through age 21 of the right to refuse to report identifying in-

formation to the Autism Registry and shall provide the parent, legal guardian, custodian or individual through age 21 with a written statement that includes the following:

1. A parent, legal guardian, custodian or individual through age 21 diagnosed with autism who refuses to report identifying information to the Autism Registry must sign the statement;

2. The statement shall become part of the permanent medical record; and

3. When a parent, legal guardian, custodian or individual through age 21 diagnosed with autism refuses to provide identifying information, the diagnosed individual's sex, county of residence, race, ethnicity, month and year of birth, diagnosis and the diagnostician information shall be submitted to the Autism Registry.

(j) When a person is registered, the Department shall inform the following individuals of the registration:

1. The parent, legal guardian or custodian if the person is 18 years of age or less;

2. The parent, legal guardian or custodian if the person is over 18 years of age and is under the care of the parent, legal guardian or custodian; or

3. The person over 18 years of age who is living independently.

(k) A health care professional shall report to the Department any person, from birth through 21 years of age, who has been diagnosed with autism and who has expired.

(*l*) The Department, in consultation with the Department of Human Services, shall maintain an up-to-date registry, which shall include a record of all reported cases of Autism that occur in New Jersey in order to conduct thorough and complete epidemiologic surveys of autism, to enable analysis of this problem, and to plan for and provide services to children with autism and their families.

(m) In accordance with N.J.S.A. 26:2-188b, a physician, psychologist or health care professional providing information to the Department shall not be deemed to be, or held liable for, divulging confidential information.

(n) The reports made pursuant to this section shall be used only by the Department and other agencies as may be designated by the Commissioner, including the Department of Human Services, and shall not otherwise be divulged or made public, so as to disclose the identity of any person to whom they relate; and, to that end, the reports shall not be included under materials available for public inspection pursuant to the "Open Public Records Act," *N.J.S.A. 47:1A-1* et seq.

NOTES:
Chapter Notes