

Table of Rare and Expensive Disease List as of July 2008		
--	--	--

ICD-9	Disease	Age Group
042	Symptomatic HIV disease/AIDS (pediatric)	0-20
V08	Asymptomatic HIV status (pediatric)	0-20
795.71	Infant with inconclusive HIV result	0-12 months
270.0	Disturbances of amino-acid transport:	0-20
	Cystinosis	
	Cystinuria	
	Hartnup disease	
270.1	Phenylketonuria – PKU	0-20
270.2	Other disturbances of aromatic-acid metabolism	0-20
270.3	Disturbances of branched-chain amino-acid metabolism	0-20
270.4	Disturbances of sulphur-bearing amino-acid metabolism	0-20
270.5	Disturbances of histidine metabolism:	0-20
	Carnosinemia	
	Histidinemia	
	Hyperhistidinemia	
	Imidazole aminoaciduria	
270.6	Disorders of urea cycle metabolism	0-20
270.7	Other disturbances of straight-chain amino-acid:	0-20
	Glucoglycinuria	
	Glycinemia (with methylmalonic acidemia)	
	Hyperglycinemia, Hyperlysinemia	
	Pipecolic acidemia	
	Saccharopinuria	
	Other disturbances of metabolism of glycine, threonine, serine, glutamine, and lysine	

ICD-9	Disease	Age Group
270.8	Other specified disorders of amino-acid metabolism: Alaninemia Ethanolaminuria Glycoprolinuria Hydroxyprolinemia Hyperprolinemia Iminoacidopathy Prolinemia Prolinuria Sarcosinemia	0-20
271.0	Glycogenosis	0-20
271.1	Galactosemia	0-20
271.2	Hereditary fructose intolerance	0-20
272.7	Lipidoses	0-20
277.00	Cystic fibrosis without ileus	0-64
277.01	Cystic fibrosis with ileus	0-64
277.02	Cystic fibrosis with pulmonary manifestations	0-64
277.03	Cystic fibrosis with gastrointestinal manifestations	0-64
277.09	Cystic fibrosis with other manifestations	0-64
277.2	Other disorders of purine and pyrimidine metabolism	0-64
277.5	Mucopolysaccharidosis	0-64
277.81	Primary Carnitine deficiency	0-64
277.82	Carnitine deficiency due to inborn errors of metabolism	0-64
277.89	Other specified disorders of metabolism	0-64
284.01	Constitutional red blood cell aplasia	0-20
284.09	Other constitutional aplastic anemia	0-20
286.0	Congenital factor VIII disorder	0-64
286.1	Congenital factor IX disorder	0-64
286.2	Congenital factor XI deficiency	0-64

ICD-9	Disease	Age Group
286.3	Congenital deficiency of other clotting factors	0-64
286.4	von Willebrand's disease	0-64
330.0	Leukodystrophy	0-20
330.1	Cerebral lipidoses	0-20
330.2	Cerebral degenerations in generalized lipidoses	0-20
330.3	Cerebral degeneration of childhood in other diseases classified elsewhere	0-20
330.8	Other specified cerebral degeneration in childhood	0-20
330.9	Unspecified cerebral degeneration in childhood	0-20
331.3	Communicating hydrocephalus	0-20
331.4	Obstructive hydrocephalus	0-20
333.2	Myoclonus	0-5
333.6	Idiopathic torsion dystonia	0-64
333.7	Symptomatic torsion dystonia	0-64
333.90	Unspecified extrapyramidal disease and abnormal movement disorder	0-20
334.0	Friedreich's ataxia	0-20
334.1	Hereditary spastic paraplegia	0-20
334.2	Primary cerebellar degeneration	0-20
334.3	Cerebellar ataxia NOS	0-20
334.4	Cerebellar ataxia in other diseases	0-20
334.8	Other spinocerebellar diseases NEC	0-20
334.9	Spinocerebellar disease NOS	0-20
335.0	Werdnig-Hoffmann disease	0-20
335.10	Spinal muscular atrophy unspecified	0-20
335.11	Kugelberg-Welander disease	0-20
335.19	Spinal muscular atrophy NEC	0-20
335.20	Amyotrophic lateral sclerosis	0-20
335.21	Progressive muscular atrophy	0-20
335.22	Progressive bulbar palsy	0-20
335.23	Pseudobulbar palsy	0-20
335.24	Primary lateral sclerosis	0-20
335.29	Motor neuron disease NEC	0-20

ICD-9	Disease	Age Group
335.8	Anterior horn disease NEC	0-20
335.9	Anterior horn disease NOS	0-20
341.1	Schilder's disease	0-64
343.0	Diplegic infantile cerebral palsy	0-20
343.2	Quadriplegic infantile cerebral palsy	0-64
344.00	Quadriplegia, unspecified	0-64
344.01	Quadriplegia, C1-C4, complete	0-64
344.02	Quadriplegia, C1-C4, incomplete	0-64
344.03	Quadriplegia, C5-C7, complete	0-64
344.04	Quadriplegia, C5-C7, incomplete	0-64
344.09	Quadriplegia, Other	0-64
359.0	Congenital hereditary muscular dystrophy	0-64
359.1	Hereditary progressive muscular dystrophy	0-64
359.2	Congenital myotonic dystrophy (Steinert's only)	0-64
437.5	Moyamoya disease	0-64
579.3	Short gut syndrome	0-20
582.0	Chronic glomerulonephritis with lesion of proliferative glomerulonephritis	0-20
582.1	Chronic glomerulonephritis with lesion of membranous glomerulonephritis	0-20
582.2	Chronic glomerulonephritis with lesion of membranoproliferative glomerulonephritis	0-20
582.4	Chronic glomerulonephritis with lesion of rapidly progressive glomerulonephritis	0-20
582.81	Chronic glomerulonephritis in diseases classified elsewhere	0-20
582.89	Other: Chronic glomerulonephritis with lesion of exudative nephritis interstitial (diffuse) (focal) nephritis	0-20

ICD-9	Disease	Age Group
582.9	Chronic glomerulonephritis with unspecified pathological lesion in kidney Nephritis specified as chronic, Nephropathy specified as chronic NOS glomerulonephritis specified as chronic Hemorrhagic glomerulonephritis specified as chronic	0-20
585.1	Chronic kidney disease, Stage I	0-20
585.2	Chronic kidney disease, Stage II (mild)	0-20
585.3	Chronic kidney disease, Stage III (moderate)	0-20
585.4	Chronic kidney disease, Stage IV (severe)	0-20
585.5	Chronic kidney disease, Stage V	0-20
585.6	End stage renal disease	0-20
585.9	Chronic kidney disease, unspecified	21-64
585, V45.1	Chronic renal failure with dialysis	21-64
741.00	Spina bifida with hydrocephalus NOS	0-64
741.01	Spina bifida with hydrocephalus cervical region	0-64
741.02	Spina bifida with hydrocephalus dorsal region	0-64
741.03	Spina bifida with hydrocephalus lumbar region	0-64
741.90	Spina bifida unspecified region	0-64
741.91	Spina bifida cervical region	0-64
741.92	Spina bifida dorsal region	0-64
741.93	Spina bifida lumbar region	0-64
742.0	Encephalocele: Encephalocystocele Encephalomyelocele Hydroencephalocele Hydromeningocele, cranial Meningocele, cerebral Menigoencephalocele	0-20
742.1	Microcephalus: Hydromicrocephaly	0-20
742.3	Congenital hydrocephalus	0-20
742.4	Other specified anomalies of brain	0-20
742.51	Other specified anomalies of the spinal cord Diastematomyelia	0-64

ICD-9	Disease	Age Group
742.53	Other specified anomalies of the spinal cord: Hydromyelia	0-64
742.59	Other specified anomalies of spinal cord: Amyelia Congenital anomaly of spinal meninges Myelodysplasia Hypoplasia of spinal cord	0-64
748.1	Nose anomaly - cleft or absent nose ONLY	0-5
748.2	Web of larynx	0-20
748.3	Laryngotracheal anomaly NEC- Atresia or agenesis of larynx, bronchus, trachea, only	0-20
748.4	Congenital cystic lung	0-20
748.5	Agenesis, hypoplasia and dysplasia of lung	0-20
749.00	Cleft palate NOS	0-20
749.01	Unilateral cleft palate complete	0-20
749.02	Unilateral cleft palate incomplete	0-20
749.03	Bilateral cleft palate complete	0-20
749.04	Bilateral cleft palate incomplete	0-20
749.20	Cleft palate and cleft lip NOS	0-20
749.21	Unilateral cleft palate with cleft lip complete	0-20
749.22	Unilateral cleft palate with cleft lip incomplete	0-20
749.23	Bilateral cleft palate with cleft lip complete	0-20
749.24	Bilateral cleft palate with cleft lip incomplete	0-20
749.25	Cleft palate with cleft lip NEC	0-20
750.3	Congenital tracheoesophageal fistula, esophageal atresia and stenosis	0-3
751.2	Atresia large intestine	0-5
751.3	Hirschsprung's disease	0-15
751.61	Biliary atresia	0-20
751.62	Congenital cystic liver disease	0-20
751.7	Pancreas anomalies	0-5
751.8	Other specified anomalies of digestive system NOS	0-10

ICD-9	Disease	Age Group
753.0	Renal agenesis and dysgenesis, bilateral only: Atrophy of kidney congenital and infantile Congenital absence of kidney(s) Hypoplasia of kidney(s)	0-20
753.10	Cystic kidney disease, bilateral only	0-20
753.12	Polycystic kidney, unspecified type, bilateral only	0-20
753.13	Polycystic kidney, autosomal dominant, bilateral only	0-20
753.14	Polycystic kidney, autosomal recessive, bilateral only	0-20
753.15	Renal dysplasia, bilateral only	0-20
753.16	Medullary cystic kidney, bilateral only	0-20
753.17	Medullary sponge kidney, bilateral only	0-20
753.5	Exstrophy of urinary bladder	0-20
756.0	Musculoskeletal--skull and face bones: Absence of skull bones Acrocephaly Congenital deformity of forehead Craniosynostosis Crouzon's disease Hypertelorism Imperfect fusion of skull Oxycephaly Platybasia Premature closure of cranial sutures Tower skull Trigonocephaly	0-20
756.4	Chondrodystrophy	0-1
756.50	Osteodystrophy NOS	0-1
756.51	Osteogenesis imperfecta	0-20
756.52	Osteopetrosis	0-1
756.53	Osteopoikilosis	0-1
756.54	Polyostotic fibrous dysplasia of bone	0-1

ICD-9	Disease	Age Group
756.55	Chondroectodermal dysplasia	0-1
756.56	Multiple epiphyseal dysplasia	0-1
756.59	Osteodystrophy NEC	0-1
756.6	Anomalies of diaphragm	0-1
756.70	Anomaly of abdominal wall	0-1
756.71	Prune belly syndrome	0-1
756.79	Other congenital anomalies of abdominal wall	0-1
759.7	Multiple congenital anomalies NOS	0-10
V46.1	Dependence on respirator	1-64
V46.9	Machine dependence NOS	1-64