

TITLE 25 HEALTH SERVICES
PART 1 DEPARTMENT OF STATE HEALTH SERVICES
CHAPTER 1 MISCELLANEOUS PROVISIONS
SUBCHAPTER D DESIGNATING INCURABLE NEURODEGENERATIVE
DISEASES

§1.61. Incurable Neurodegenerative Diseases.

(a) An incurable neurodegenerative disease is a condition, injury, or illness:

(1) that occurs when nerve cells in the brain or peripheral nervous system lose function over time; and

(2) for which there is no known cure.

(b) A qualifying physician under Texas Occupations Code, Chapter 169, may prescribe low-THC cannabis to a patient with a documented diagnosis of one or more of the following incurable neurodegenerative diseases:

(1) Incurable Neurodegenerative Diseases with Adult Onset:

(A) Motor Neuron Disease:

(i) Amyotrophic lateral sclerosis;

(ii) Spinal-bulbar muscular atrophy; and

(iii) Spinal Muscular Atrophy.

(B) Muscular Dystrophies:

(i) Duchenne Muscular Dystrophy;

(ii) Central Core; and

(iii) Facioscapulohumeral Muscular Dystrophy.

(C) Freidrich's Ataxia.

(D) Vascular dementia.

(E) Charcot Marie Tooth and related hereditary neuropathies.

(F) Spinocerebellar ataxia.

(G) Familial Spastic Paraplegia.

(H) Progressive dystonias DYT genes 1 through 20.

(I) Progressive Choreas: Huntington's Disease.

(J) Amyloidoses:

(i) Alzheimer's Disease;

(ii) Prion Diseases:

(I) Creutzfeldt-Jakob Disease;

(II) Gerstmann-Strausler-Scheinker Disease;

(III) Familial or Sporadic Fatal Insomnia; and

(IV) Kuru.

(K) Tauopathies.

(i) Chronic Traumatic Encephalopathy;

(ii) Pick Disease;

(iii) Globular Glial Tauopathy;

(iv) Corticobasal Degeneration;

(v) Progressive Supranuclear Palsy;

(vi) Argyrophilic Grain Disease;

(vii) Neurofibrillary Tangle dementia, also known as Primary Age-related Tauopathy; and

(viii) Frontotemporal dementia and parkinsonism linked to chromosome 17 caused by mutations in MAPT gene.

(L) Synucleinopathies:

(i) Lewy Body Disorders:

(I) Dementia with Lewy Bodies; and

(II) Parkinson's Disease; and

(ii) Multiple System Atrophy.

(M) Transactive response DNA-binding protein-43 (TDP-43) Proteinopathies:

(i) Frontotemporal Lobar Degeneration;

(ii) Primary Lateral Sclerosis; and

(iii) Progressive Muscular Atrophy.

(2) Incurable Neurodegenerative Diseases with Pediatric Onset:

(A) Mitochondrial Conditions:

(i) Kearns Sayers Syndrome;

(ii) Mitochondrial Encephalopathy Ragged Red Fiber;

(iii) Mitochondrial Encephalopathy Lactic Acidosis Stroke;

(iv) Neuropathy, Ataxia, and Retinitis Pigmentosa;

(v) Mitochondrial neurogastrointestinal encephalopathy;

(vi) Polymerase G Related Disorders:

(I) Alpers-Huttenlocher syndrome;

(II) Childhood Myocerebrohepatopathy spectrum;

(III) Myoclonic epilepsy myopathy sensory ataxia; and

(IV) Ataxia neuropathy spectrum;

(vii) Subacute necrotizing encephalopathy, also known as Leigh syndrome;

(viii) Respiratory chain disorders complex 1 through 4 defects: Co Q biosynthesis defects;

(ix) Thymidine Kinase;

(x) Mitochondrial Depletion syndromes types 1 through 14:

(I) Deoxyguanosine kinase deficiency;

(II) SUCLG1-related mitochondrial DNA depletion syndrome, encephalomyopathic form with methylmalonic aciduria; and

(III) RRM2B-related mitochondrial disease.

(B) Creatine Disorders:

(i) Guanidinoacetate methyltransferase deficiency;

(ii) L-Arginine/glycine amidinotransferase deficiency; and

(iii) Creatine Transporter Defect, also known as SLC 6A8.

(C) Neurotransmitter defects:

(i) Segawa Disease, also known as Dopamine Responsive Dystonia;

(ii) Guanosine triphosphate cyclohydrolase deficiency;

(iii) Aromatic L-amino acid decarboxylase deficiency;

(iv) Monoamine oxidase deficiency;

(v) Biopterin Defects:

(I) Pyruvoyl-tetrahydropterin synthase;

(II) Sepiapterin reductase;

(III) Dihydropteridine reductase; and

(IV) Pterin-4-carbinolamine dehydratase.

(D) Congenital Disorders of Glycosylation.

(E) Lysosomal Storage Diseases:

(i) Mucopolysaccharidosis:

(I) Mucopolysaccharidosis Type I, also known as Hurler Syndrome or Scheie Syndrome;

(II) Mucopolysaccharidosis Type II, also known as Hunter Syndrome;

(III) Mucopolysaccharidosis Type III, also known as Sanfilippo A and B; and

(IV) Mucopolysaccharidosis Type IV, also known as Maroteaux-Lamy; and

(V) Mucopolysaccharidosis Type VII, also known as Sly.

(ii) Oligosaccharidoses:

(I) Mannosidosis;

(II) Alpha-fucosidosis;

(III) Galactosialidosis;

(IV) Asparylglucosaminuria;

(V) Schindler; and

(VI) Sialidosis;

(iii) Mucopolipidoses:

(I) Mucopolipidoses Type II, also known as Inclusion Cell disease; and

(II) Mucopolipidoses Type III, also known as pseudo-Hurler polydystrophy;

(iv) Sphingolipidoses:

(I) Gaucher Type 2 and Type 3;

(II) Neimann Pick Type A and B;

(III) Neimann Pick Type C;

(IV) Krabbe;

(V) GM1 gangliosidosis;

(VI) GM2 gangliosidosis also known as Tay-sachs and Sandhoff Disease;

(VII) Metachromatic leukodystrophy;

(VIII) Neuronal ceroid lipofuscinosis types 1-10 including Batten Disease; and

(IX) Farber Disease; and

(v) Glycogen Storage-Lysosomal: Pompe Disease.

(F) Peroxisomal Disorders:

(i) X-linked adrenoleukodystrophy;

(ii) Peroxisomal biosynthesis defects:

(I) Zellweger syndrome:

(II) Neonatal Adrenoleukodystrophy; and

(iii) D Bidirectional enzyme deficiency.

(G) Leukodystrophy:

(i) Canavan disease;

(ii) Pelizaeus-Merzbacher disease;

(iii) Alexander disease;

(iv) Multiple Sulfatase deficiency;

(v) Polyol disorders;

(vi) Glycine encephalopathy, also known as non-ketotic hyperglycinemia;

(vii) Maple Syrup Urine Disease;

(viii) Homocysteine re-methylation defects;

(ix) Methylenetetrahydrofolate reductase deficiency severe variant;

(x) L-2-hydroxyglutaric aciduria;

(xi) Glutaric acidemia type 1;

(xii) 3-hydroxy-3-methylglutaryl-CoA lyase deficiency;

(xiii) Galactosemia;

(xiv) Manosidosis alpha and beta;

(xv) Sialidosis;

(xvi) Peripheral neuropathy types 1 through 4;

(xvii) Pyruvate Dehydrogenase Deficiency;

(xviii) Pyruvate Carboxylase Deficiency;

(xix) Refsum Disease; and

(xx) Cerebral Autosomal Dominant Arteriopathy with Sub-cortical Infarcts and Leukoencephalopathy.

(H) Fatty Acid Oxidation:

(i) Trifunctional protein deficiency; and

(ii) Long-chain L-3 hydroxyacyl-CoA dehydrogenase deficiency.

(I) Metal Metabolism:

(i) Wilson Disease;

(ii) Pantothenate Kinase Associated Neurodegeneration; and

(iii) Neurodegeneration with brain iron accumulation.

(J) Purine and Pyrimidine Defects:

(i) Adenylosuccinate synthase Deficiency;

(ii) 5-aminoimidazole-4-carboxamide ribonucleotide transformylase deficiency;

(iii) Hypoxanthine-guanine phosphoribosyltransferase Deficiency also known as Lesch-Nyhan disease;

(iv) Dihydropyrimidine dehydrogenase Deficiency; and

(v) Dihydropyrimidinase Deficiency.

(c) A treating physician of a patient suffering from an incurable neurodegenerative disease not listed in subsection (b) of this section may submit a request to the department to have a disease added.

(d) A request under subsection (c) of this section shall be submitted to the department on a form prescribed by the department, which can be found on the department's website at <https://www.dshs.texas.gov/chronic/default.shtm>.

(e) After review of the submitted documentation, the department may request additional information or make a determination.