

NEUROLOGYReferral <u>Guidance Sheet</u>



To qualify for a wish, a child must meet these criteria at the time of referral:

- 1. Older than 2½ years and under 18 years
- 2. Has not received a wish from another wish-granting organization
- 3. Diagnosed with a condition currently placing the child's life in jeopardy

Usually qualifying Neurology conditions:

- Alpers disease
- Cerebral palsy with associated life-threatening complications
 - o e.g., intractable seizures, compromised respiratory failure
- Congenital neuromuscular disease with respiratory or cardiac complications including:
 - o Myotonic muscular dystrophy
 - o Duchenne muscular dystrophy
 - o Spinal muscular atrophy types 1 and 2
- Epilepsy/uncontrolled seizures that are:
 - o Intractable
 - o Refractory
 - o Treatment-resistant
- Familial dysautonomia (Riley-Day)
- Friedreich's ataxia
- Huntington's disease

- Leigh syndrome
- Lennox-Gastaut syndrome that is:
 - o Intractable
 - o Treatment-resistant
- Leukodystrophy
- Moyamoya disease
- Neurodegenerative disease with significantly shortened life expectancy
- Neuronal brain iron accumulation (NBIA)
- Progressive cerebrovascular disease (e.g., stroke) with ongoing life-threatening complications
- Profound neurodevelopmental delay with associated lifethreatening comorbidities requiring significant and ongoing life-sustaining medical support
- Rett syndrome
- Tuberous sclerosis, involving the brain or spinal cord

Other conditions that may be eligible for a wish with complicating comorbidities:

- Arhinencephaly
- Encephalopathy
- Hydrocephalus
- Megalencephaly

- Myopathy
- Neurofibromatosis
- Spina bifida
- Many other conditions not listed

