

*I wish to go to
Alaska*

Josephine, 14
neuromuscular disorder



Neurology Referral Guidance Sheet

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

1. Older than 2½ years and younger than 18 years
2. Has not received a wish from another wish-granting organization
3. Diagnosed with a **critical illness** (i.e. a progressive, degenerative or malignant condition) that, despite adherence to the treatment plan, is currently placing the child's life in jeopardy

Qualifying Neurology Conditions:

- ✧ Alpers disease
- ✧ Batten disease
- ✧ Congenital neuromuscular disease with progressive loss of motor function in children who are symptomatic and currently experiencing respiratory or cardiac complications (e.g., myotonic muscular dystrophy)
- ✧ Duchenne muscular dystrophy
- ✧ Epilepsy/Lennox-Gastaut/uncontrolled motor seizures that are currently defined by the provider as:
 - Tonic, atonic, or tonic-clonic **and**
 - With a failure of two or more anti-seizure medications **and**
 - With continued, repeated breakthrough tonic, atonic or tonic-clonic seizures requiring rescue medication(s) and/or unplanned admission (e.g., approximately one event per month)
- ✧ Huntington's disease, symptomatic
- ✧ Leigh syndrome with MRI changes
- ✧ Leukodystrophy, progressive
- ✧ Moyamoya disease
- ✧ Neurodegenerative disease with MRI findings of progression and qualifying respiratory or cardiac complications
- ✧ Neuronal brain iron accumulation (NBIA)
- ✧ Progressive cerebrovascular disease (e.g., stroke) with ongoing life-threatening complications
- ✧ Rett syndrome
- ✧ Riley-Day
- ✧ Spinal muscular atrophy, types 1 and 2
- ✧ Tuberous sclerosis involving the brain and/or spinal cord

There are other conditions that may be eligible for a wish when the condition includes life-threatening comorbidities that are currently placing the child's life in jeopardy. These conditions will be reviewed on a case-by-case basis. Please include detailed information on these conditions when submitting the **Diagnosis Verification Form**.