




Metabolic

Referral Guidance Sheet




*I wish to stay
in a treehouse
in Maine*

Sylvi, 8
metabolic disorder

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 Metabolic Conditions:

- ✧ Alexander disease (symptomatic)
 - ✧ Barth syndrome
 - ✧ Gaucher disease – type 2
 - ✧ Infantile Pompe
 - ✧ Krabbe disease
 - ✧ Lesch-Nyhan syndrome
 - ✧ Maple syrup urine disease with a history of hyperleucemia event occurring after diagnosis
 - ✧ Metachromatic leukodystrophy, progressive
 - ✧ Mucopolysaccharidosis disorders (symptomatic) such as:
 - Hunter syndrome
 - Hurler syndrome
 - Sanfilippo syndrome
 - ✧ Niemann-Pick disease
 - ✧ Peroxisomal disorder
 - ✧ Pyruvate dehydrogenase with disease progression
 - ✧ Sphingolipidosis with symptoms in the pediatric period:
 - GM1 gangliosidosis
 - Tay-Sachs
 - ✧ Urea cycle (CPS, OTC, citrullinemia) and organic acidemia disorders (methylmalonic and propionic) with a history of a hyperammonemic event occurring after diagnosis
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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.