

Version Wednesday, 22 March 2023

Wish Eligibility Criteria are child-focused, dynamic and inclusive. The guidelines and principles shall evolve with medical advancement. In determining wish eligibility and the child's medical needs relating to a wish, there will be a reliance upon the advice of the primary treating physician and your local medical advisory.

Medical principles of wish eligibility

- 1. A child or a young adult aged 3 to 17 years old
- 2. Has not received a wish from another wish-granting organization
- 3. Diagnosed with a critical illness condition currently placing the child's life in a life-threatening stage or with extreme long-term complications.*

*Critical illnesses include, but are not restricted to: childhood cancers, certain types of muscular dystrophy, certain neurological or genetic diseases, cardiac disorders, renal failure and traumatic injuries. Please speak with us or contact your doctor for more information.

Principles to determine critical illness conditions

- 1. Children whose current medical condition requires high-risk therapy to survive may qualify for a wish.
- 2. Children who are dependent on technology to survive may qualify for a wish.
- 3. Children with chronic conditions who demonstrate extreme long-term complications may qualify for a wish.
- 4. Children at high risk of death not covered by other criteria on this list may qualify for a wish.



RHEUMATOLOGY Referral Guidance Sheet



USUALLY qualifying Rheumatology CONDITIONS:

- Antiphospholipid syndrome with recurrent thrombosis/active disease (not just positive antibody titers)
- Autoinflammatory conditions e.g., TRAPS, CINCA/NOMID, HIDS, CANDLE, DIRA
- Chronic vasculitis:
 - Eosinophilic granulomatosis with polyangiitis
 - o Granulomatosis
 - o Microscopic polyangiitis
 - o Polyangiitis
 - o Polyarteritis nodosa
 - o Takayasu arteritis

- Juvenile dermatomyositis
 - With any end-organ involvement, calcinosis, or otherwise recalcitrant (greater than one year of treatment or two or more relapses)
- Mixed connective tissue disease with end-organ involvement
- Pediatric systemic lupus erythematous with end-organ involvement
- Polychondritis resulting in end-organ damage
- Progressive Systemic Sclerosis (Systemic Scleroderma)
- Systemic JRA/JIA with macrophage activation syndrome (MAS)
 Referred within 12 months of MAS

episode or having continuing MAS issues

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

• Complications from immunosuppressive therapy

• Many other conditions not listed



PULMONARYReferral Guidance Sheet



USUALLY qualifying Pulmonary CONDITIONS:

- Chronic hypoxemia requiring supplemental oxygen
- Chronic respiratory failure
- Chronic ventilator dependence
- Cystic fibrosis
- Lung transplant
- Moderate to severe lung disease secondary to chemotherapy and radiation
- Placement on the lung transplant list
- Progressive histiocytosis, including multifocal
- Progressive interstitial lung disease associated with immunodeficiency, autoimmune disease, or immune dysregulation

- Pulmonary fibrosis
- Pulmonary graft versus host disease
- Pulmonary hypertension
- Pulmonary lymphangiectasia
- Severe respiratory compromise incompletely responsive to therapy and resulting in recurrent life-threatening episodes
- Surfactant protein dysfunction
- Tracheostomy placement for chronic respiratory failure or severe airway obstruction
- Complex Severe Bronchiectasis

- Acute respiratory failure
- Bronchopulmonary dysplasia
- Children having a tracheotomy with oxygen requirements (depending on the underlying medical diagnosis or reason for the tracheotomy)
- Chronic obstructive pulmonary disease

- Primary ciliary dyskinesia
- Severe asthma
- Severe restrictive lung disease
- Complications from immunosuppressive therapy
- Many other conditions not listed



ONCOLOGYReferral Guidance Sheet



USUALLY qualifying Oncology CONDITIONS:

- Bone marrow/stem cell transplant
- Low grade tumors with any of the following criteria:
 - Requiring chemotherapy infusions or radiation
 treatment and referred within one year of completion of the above mentioned treatment
 - Requiring more than one major surgery, such as craniotomy
 - Location of tumor requiring ongoing medical intervention (e.g., seizures or endocrine deficit, significant functional impairment such as paralysis, or other major neurologic impairment)
 - Associated with extensive complications
 (e.g.; a lengthy unplanned hospital stay)

- Malignant neoplasm and neoplasm of unspecified/uncertain behavior
- Requiring and referred within one year of completion
 - of chemotherapy infusions or radiation treatment
- Status post bone marrow/stem cell transplant (with ongoing life-threatening complications)

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

• Complications from immunosuppressive therapy

• Many other conditions not listed





NEUROLOGYReferral Guidance Sheet



USUALLY qualifying Neurology CONDITIONS:

- Alpers disease
- Cerebral palsy with associated lifethreatening complications
 - o e.g., intractable seizures, compromised respiratory failure
- Congenital neuromuscular disease with respiratory or cardiac complications including:
 - Myotonic muscular dystrophy
 - Duchenne muscular dystrophy
 - 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 life- threatening comorbidities requiring significant and ongoing life-sustaining medical support
- Rett syndrome
- Tuberous sclerosis, involving the brain or spinal cord

- Arhinencephaly
- Encephalopathy
- Hydrocephalus
- Megalencephaly

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



NEPHROLOGYReferral Guidance Sheet



USUALLY qualifying Nephrology CONDITIONS:

- Chronic kidney disease (stage 3 or greater) with:
 - o Multiple acute illnesses/exacerbations in the last year requiring hospitalization
- Dialysis dependent renal disease
- Kidney transplant

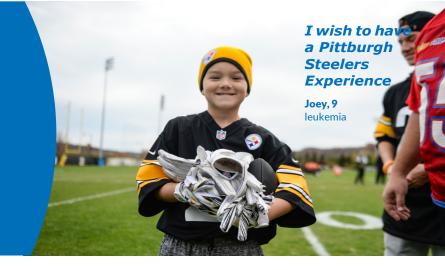
- Kidney diseases dependent on long-term infusions and/or plasma exchange
 e.g., atypical hemolytic uremic syndrome requiring chronic anticomplement therapy to stay in remission
- Status post kidney transplant (with ongoing life-threatening complications)

- Refractory nephrotic syndrome

 e.g.; multiple acute illnesses or relapses
 requiring infusion medication and multiple
 immunosuppressive medications
- Complications from immunosuppressive therapy
- Many other conditions not listed



IMMUNOLOGY & INFECTIOUS DISEASE Referral Guidance Sheet



USUALLY qualifying Immunology and INFECTIOUS DISEASE CONDITIONS:

- Bone marrow transplant
- Immunodeficiencies with:
 - Severe autoimmune complications and/or significantly diminished life expectancy
- Primary immunodeficiencies requiringlifelong treatment
 - Life expectancy is anticipated to be significantly
 shortened if the treatment is not available
 - o e.g., Wiskott-Aldrich, Bruton's agammaglobulinemia, chronic granulomatous disease

- Primary immunodeficiency diseases resulting in frequent unplanned hospitalizations where infection is not well controlled
- Severe combined immunodeficiency disease (SCID)
- Status post bone marrow transplant (with ongoing life-threatening complications)



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

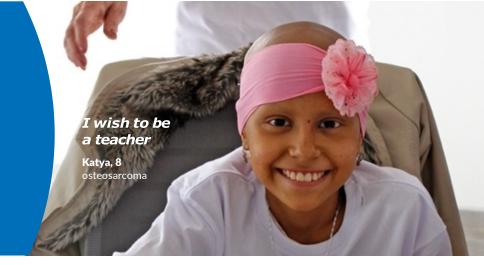
 Complications from immunosuppressive therapy

- HIV
- Many other conditions not listed





HEMATOLOGYReferral Guidance Sheet



USUALLY qualifying Hematology CONDITIONS:

- Aplastic anemia
- Bone marrow transplant
- Hemophagocytic lymphohistiocytosis
- Severe congenital or acquired bleeding disorders with:
 - Hemorrhage in vital organs resulting in significant morbidity (e.g., intracranial hemorrhage with neurodeficits, organ injury requiring intensive supportive care, etc.)
 - High titre hemophilic inhibitors resulting in repeated lifethreatening bleeding episodes
- Severe combined immunodeficiency (SCID)
- Stem cell transplant (within one year)
- Severe congenital or acquired blood cell disorders with:
 - o Treatment requiring chemotherapy infusions
 - Serious complications resulting from transfusion therapy (e.g., iron overload)

- Sickle cell disease (Hb-SS, Hb-SC) orthalassemia with severe or chronic complications such as:
 - Acute chest syndrome
 - Splenic sequestration
 - o Stroke or severe cerebrovascular disease
 - o Necessary regular transfusion
 - Pulmonary hypertension
 - o Multiple severe pain crises within past year
 - End organ damage requiring additional supportive measures



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

 Complications of immunodeficiency or from immunosuppressive therapy

- Coagulation disorders
- Many other conditions not listed



GENETICSReferral Guidance Sheet



USUALLY qualifying GENETICS CONDITIONS:

- Barth syndrome
- Congenital anomaly, chromosomal, or single gene condition with associated life-threatening complications such as:
 - o Intractable seizures
 - Structural upper airway abnormalities or chronic pulmonary symptoms
 - Heart anomalies meeting cardiology guidance
 - o Chronic renal failure
 - Associated major gastrointestinal dysfunctions

- Skeletal dysplasias or dysostoses with chronic or degenerative pulmonary complications
- Trisomy 13 and 18



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

• Complications from immunosuppressive therapy • Many other conditions not listed





GASTROENTEROLOGYReferral Guidance Sheet



USUALLY qualifying GASTROENTEROLOGY CONDITIONS:

- Bowel/Intestinal transplant
- Chronic progressive liver disease with decompensation
- Hepatopulmonary syndrome
- Inflammatory bowel disease resulting in short gut disease with:
 - o Prolonged parenteral support
 - Complications resulting from immunosuppressive therapy or surgery

- Liver failure
- Liver transplantation
- Malignancy or inherited premalignant conditions
- Portal hypertension
- Short bowel syndrome or intestinal failure requiring prolonged parenteral (TPN)support
- Status post liver transplant (with ongoing life-threatening complications)

- Atresia of bile ducts
- Complications from immunosuppressive therapy
- Crohn's disease
- Hirschsprung's disease

- Pancreatitis
- Ulcerative colitis
- Many other conditions not listed





ENDOCRINOLOGY & METABOLICCONDITIONS Referral Guidance Sheet



USUALLY qualifying Endocrinolgy CONDITIONS:

- Disorder of glycosaminoglycan metabolism
- Disorder of urea cycle metabolism
- Fabry (Anderson) disease
- Gaucher disease
- Hyperinsulinism with persistent hypoglycemia afterpancreatectomy
- Krabbe disease
- Lesch-Nyhan syndrome
- Maple syrup urine disease
- Metachromatic leukodystrophy
- Multiple endocrine neoplasia syndromes with evidence of cancer
- Niemann-Pick disease

- Panhypopituitarism requiring hormone replacement with hydrocortisone and/or desmopressin
- · Peroxisomal disorder
- Prader-Willi syndrome with comorbidities
- Sphingolipidosis
- Tay-Sachs disease
- Thyroid cancer
 - Requiring chemotherapy infusions or radiation treatment and referred within one year of completion of the above mentioned treatment
- X-linked adrenoleukodystrophy (all others will be reviewed on a case-by-case basis)







CARDIOLOGYReferral Guidance Sheet



USUALLY qualifying Cardiology CONDITIONS:

- Complex congenital heart disease, such as:
 - Single ventricle
 - o Double inlet left ventricle
 - o Tricuspid atresia
 - o Aortic atresia
 - o Mitral atresia
 - o Hypoplastic left heart syndrome
- Congestive heart failure
- Hypertrophic, restrictive, and/or arrhythmogenic right ventricular cardiomyopathy (ARVC)
- Implanted cardiac defibrillator
- Implanted ventricular assist device
- Left ventricular heart failure

- Long QT syndrome
- Necessary frequent hospitalizations after repair of a congenital heart defect(routine studies requiring hospitalization are not included)
- Placement on the heart transplant list
- Pulmonary arterial hypertension
- Recipient of a heart or heart-lung transplant
- Status post Fontan procedure
- Tetrology of Fallot with pulmonary atresia and major aortopulmonary collaterals
- Ventricular fibrillation



- Common arterial trunk
- Complications from immunosuppressive therapy
- Double outlet right ventricle
- Discordant ventriculoarterial connection
- Heart failure

- Pacemaker implantation
- Subaortic stenosis
- Tetralogy of Fallot
- Many other conditions not listed





Transplant criteria guidelines

- 1. All children with a transplant are always eligible for a wish (even for children with transplant prior to the age of eligibility) if they are between the age of 3 to 18 at the time of referral.
- 2. The Medical Advisory Committee recommends that healthcare professionals refer children within the first year after undergoing a transplant. This is when the child may need a wish the most. A wish is less likely to be impactful to a child the further the child is away from their transplant. Some children may not be able to participate in certain kinds of wishes in the first year following the transplant, and in some cases the wish may need to be postponed. Still we encourage affiliates and their medical advisory team to discuss the variety of wishes a child may have following a transplant. Affiliates are encouraged to be mindful of the medical and voluntary hold policies and to have open and honest discussions with the child's medical teams and families about timely wishes.