Approval date: _____

Assigned to: _____

Budget: _____

WISH APPLICATION

Date of Request: _____

WISH APPLICATION INFORMATION:

Name of wish child: _____ Sex: _____ Age: _____

Address/Apt. #: _____

City/State/Zip: _____

Date of birth: _____

Parent(s)/Guardian(s): _____

_____

(Please identify relationship to wish child for each parent/guardian listed)

Parent/Guardian Phone: _____ (Home) Family Member: _____

Parent/Guardian Phone: _____ (Work/Cell) Family Member: _____

Email Address: _____

Please list name, age, and birth date for all siblings or other family members who will participate in this Wish and reside in the home with the Child. Only family members residing in the immediate household are eligible.

Name: _____ Age/DOB: _____ Relationship to child: _____

Name: _____ Age/DOB: _____ Relationship to child: _____

Name: _____ Age/DOB: _____ Relationship to child: _____

Name: _____ Age/DOB: _____ Relationship to child: _____

Name: _____ Age/DOB: _____ Relationship to child: _____

Name: _____ Age/DOB: _____ Relationship to child: _____

Has this Wish Child or any other child in the household previously received or have a pending Wish from Carolina Sunshine for Children or any other wish granting organization? Yes □ No □

If yes, child's name: _____ Wish Organization: _____ Date: _____

WISH INFORMATION:

Requested Wish: _____

_____

_____

Requested Wish dates: _____

Why do you feel this child needs this wish? _____

_____

_____

_____

Wishes must be completed within one year following their approval. After that time a new Wish Application must be submitted for re-approval by the Carolina Sunshine Board of Directors.

THIS AREA FOR PHYSICIAN'S USE ONLY:
This Wish Application must be signed by the Attending Physician, confirming that the Child's illness is life-threatening at the time this Wish Application is submitted.

Medical Diagnosis:

_____

_____

_____

Please include specific details on the Physician's Statement of Wish Child Qualification form (page 4 and Appendix A) and return as part of the Wish Application.

Attending/Referring Physician: _____

Office Address:_____

City/State/Zip: _____

Physician's Phone: _____ Physician's Fax: _____

Physician's Signature:_____

Wish Requested by: _____

Address: _____

City/State/Zip: _____

Phone: _____ Email: _____

As the person or organization requesting a Wish from Carolina Sunshine for Children, Inc., I certify that the above information is complete, accurate, and true.

By: _____ Date: _____

Carolina Sunshine for Children
Publicity Release

I/We

1. _____, Parent(s)/Guardian(s) of
Names of Parent(s)/Guardian(s)

_____ and _____
Name of Wish Child — Name of Accompanying Brother(s) and/or Sister(s)

2. AND/OR _____, Parent(s)/Guardian(s) of
Names of Parent(s)/Guardian(s)

_____
Accompanying Child(ren)

3. AND/OR _____
Accompanying Adult(s) 18 Years or Older

hereby expressly acknowledge that I/we have requested that I/we be allowed to participate in a wish being granted to the above-named child by CAROLINA SUNSHINE FOR CHILDREN, INC.

By my/our signature(s) set forth below, on my/our behalf and on behalf of the above-named child, and in consideration of CAROLINA SUNSHINE FOR CHILDREN, INC. granting said wish, I/we authorize CAROLINA SUNSHINE FOR CHILDREN, INC. or any of its agents, directors, officers, servants or employees to photograph, film, and/or electronically record interviews with me/us in such manner as they choose.

I/We further authorize CAROLINA SUNSHINE FOR CHILDREN, INC. or any person or organization participating in the taking of said photographs, films, and/or electronically recorded interviews to distribute now or at any time in the future, all of said photographs, films, and/or electronically recorded interviews to anyone including the general public, magazines, newspapers, television and radio stations, and/or any other organization or person that customarily presents information or news to the general public.

I/We further authorize CAROLINA SUNSHINE FOR CHILDREN, INC. or any of its agents, directors, officers, servants or employees to copy and/or electronically record any correspondence from me/us to distribute now or at any time in the future to anyone including the general public in such manner as they choose.

I/We further authorize CAROLINA SUNSHINE FOR CHILDREN, INC. to disclose to the general public, as well as to television and radio stations, newspapers or magazines, or any other form of news or public media, now or at any time in the future, my/our name(s) and the details of the wish in which I am/we are participating.

I/We hereby promise that I/we have read the foregoing Release and have executed it freely and voluntarily.

_____	_____	_____
Witness	Parent/Guardian	Date
_____	_____	_____
Witness	Parent/Guardian	Date
_____	_____	_____
Witness	Accompanying Other Adult	Date
_____	_____	_____
Witness	Accompanying Other Adult	Date

Carolina Sunshine for Children
Physician's Statement of Wish Child Qualification

Purpose statement: To grant wishes to children ages 3 through 18 years (or 21 years on case-by-case basis) who present with a life-threatening condition at the time of wish referral.

Wish Child's name: _____

Please review the Definitions below and check any/all that apply for this child:

__ 1. Progressive disorders – those that become more severe over time.

__ 2. Degenerative disorders – characterized by a gradual deterioration of the body or mind that would lead to increased impairment or loss of function.

__ 3. Malignant – cancerous, tending to metastasize, threatening to life.

Possible Qualifying Diagnoses that would be considered can be found in Appendix A (attached). Please review and document below the appropriate diagnosis/diagnoses below:

_____

_____

_____

_____

The list in Appendix A is not all-inclusive. The Board of Directors of Carolina Sunshine for Children will review all requests for possible approval. **Please list below any specific diagnoses and medical information to assist in our review process.**

_____

_____

_____

_____

_____

I certify that this Wish child currently has a life-threatening condition and the above medical information is accurate to the best of my knowledge.

Physician's signature: _____ Date: _____

End of Wish Application

The information contained in this Wish Application is confidential.
Mail applications to: Carolina Sunshine for Children, Inc.
P.O. Box 1803 ● Columbia, South Carolina, 29202

Appendix A - Carolina Sunshine for Children
List of Possible Qualifying Diagnoses

General Carolina Sunshine Wish Conditions:

1. Carolina Sunshine for Children grants wishes to children with serious or life-threatening illnesses.
2. The Child must be age 3-18 (up to 21 years old will be assessed on a case-by-case basis).
3. The Child must be a resident of South Carolina. A Child being treated at a medical facility outside of the state of South Carolina is still eligible.
4. The child must not have previously been a recipient of a Wish from Carolina Sunshine for Children or any other wish-granting organization.
5. Only one Wish will be granted per Child.
6. Only members of the immediate household and family may participate in the wish. This includes brothers, sisters, moms and dads. Contact a Carolina Sunshine for Children Board Member regarding Foster families.
7. The Wish must be the Wish of the Child.
8. Carolina Sunshine for Children does not grant wishes for children to receive motor vehicles, pools, or firearms.

There may be medical conditions not described below which can be considered on a case-by-case basis to determine if criteria is met for eligibility.

CARDIOLOGY

- ☐ Complex congenital heart disease, such as: Single ventricle, Double inlet left ventricle, Tricuspid atresia, Aortic atresia, Mitral atresia, Hypoplastic left heart syndrome, Pulmonary atresia, Shone's complex
- ☐ Congestive heart failure
- ☐ Hypertrophic, restrictive, dilated, 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
- ☐ Tetralogy of Fallot with pulmonary atresia and major aortopulmonary collaterals
- ☐ Ventricular fibrillation
- ☐ May be eligible with complicating comorbidities: Common arterial trunk, Complications from immunosuppressive therapy, Double outlet right ventricle, Discordant ventriculoarterial connection, Heart failure, Pacemaker implantation, Subaortic stenosis, Tetralogy of Fallot, Myocarditis with significant sequelae

ENDOCRINOLOGY

- ☐ Hyperinsulinism with persistent hypoglycemia after pancreatectomy or on Diazoxide
- ☐ Multiple endocrine neoplasia (MEN) syndromes with evidence of cancer
- ☐ Panhypopituitarism requiring hormone replacement with hydrocortisone and/or desmopressin
- ☐ 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)
- ☐ X-linked hypophosphatemic rickets
- ☐ Congenital adrenal hyperplasia

METABOLIC CONDITIONS

- ☐ Congenital defects in glycosylation
- ☐ Cystinosis
- ☐ Disorders of glycosaminoglycan metabolism, mucolipidosis, oligosaccharidoses
- ☐ Disorder of urea cycle metabolism
- ☐ Fabry (Anderson) disease
- ☐ Gaucher disease
- ☐ Glycogen storage disorders
- ☐ Krabbe disease
- ☐ Lesch-Nyhan syndrome
- ☐ Amino acidopathies, including but not limited to: Maple syrup urine disease, Tyrosinemia, Nonketotic hyperglycemia
- ☐ Menke disease
- ☐ Metachromatic leukodystrophy
- ☐ Mitochondrial/energy production defects
- ☐ Neurotransmitter defects
- ☐ Niemann-Pick disease
- ☐ Organic acidemias
- ☐ Peroxisomal disorder
- ☐ Prader-Willi syndrome with comorbidities
- ☐ Sphingolipidosis
- ☐ Tay-Sachs disease
- ☐ Wilson disease

GASTROENTEROLOGY

- ☐ Bowel/intestinal transplant
- ☐ Chronic progressive liver disease with decompensation
- ☐ Hepatopulmonary syndrome
- ☐ Irritable Bowel Disease resulting in short gut disease with prolonged parental support or complications resulting from immunosuppressive therapy or surgery
- ☐ Chronic liver failure or end-stage liver disease
- ☐ Liver transplant
- ☐ Malignancy or inherited premalignant conditions
- ☐ Portal hypertension
- ☐ Short bowel syndrome or intestinal failure requiring prolonged TPN support
- ☐ Status post liver transplant (with on-going life-threatening complications)
- ☐ May be eligible with complicating comorbidities: Atresia of the bile ducts, Complications from immunosuppressive therapy, Crohn's disease, Hirschsprung's disease, Pancreatitis, Ulcerative colitis

GENETICS

- Congenital anomalies, chromosome abnormalities, or other genetic conditions with associated life-threatening complications such as: Intractable seizures, Structural upper airway and abnormalities or chronic pulmonary symptoms, Heart anomalies meeting cardiology guidance, Chronic renal failure, Associated major gastrointestinal dysfunctions, Childhood-onset neurodegenerative symptoms
- Chromosome abnormalities: Trisomy 13, Trisomy 18
- Neurodegenerative disorders: Neuronal ceroid lipofuscinosis (Batten disease), adrenoleukodystrophy, metachromatic leukodystrophy, San Filippo syndrome
- Muscular dystrophies with potential childhood onset life-threatening pulmonary or cardiac complications: Congenital myotonic dystrophy, Duchenne muscular dystrophy
- Metabolic disorder, or inborn error of metabolism, with life-threatening metabolic crises resulting in progressive developmental regression
- Skeletal dysplasias with chronic or degenerative pulmonary or multi-organ system complications: Jeune, Rhizomelic chondrodysplasia punctata type 1
- Other genetic conditions with child-hood onset progressive neurodevelopmental and/or multi-organ system involvement: Barth syndrome, Rett syndrome, severe forms of mucopolysaccharidoses (MPS disorders) and mucolipidosis (ML) disorders

HEMATOLOGY

- Aplastic anemia and other bone marrow failure syndromes
- Bone marrow transplant (within one year)
- Hemophagocytic lymphohistiocytosis
- Severe congenital or acquired bleeding disorders with: Hemorrhage in vital organs resulting in significant morbidity (e.g. intracranial hemorrhage with neuro deficits, organ injury requiring intensive supportive care, etc.)
- Severe combined immunodeficiency (SCID)
- Stem cell transplant (within one year)
- Severe congenital or acquired blood cell disorders with: Treatment requiring chemotherapy infusions, Serious complications resulting from transfusion therapy (e.g. iron overload)
- Sickle cell disease (Hb-SS, Hb-SC) or thalassemia with severe or chronic complications such as: Acute chest syndrome, Splenic sequestration, Stroke or severe cerebrovascular disease, Necessary regular transfusion, Pulmonary hypertension, Multiple severe pain crises within past year, End organ damage requiring additional supportive measures
- May be eligible with complicating comorbidities: Complications of immunodeficiency or from immunosuppressive therapy, Coagulation disorders

IMMUNOLOGY

- Bone marrow transplant (within one year of transplant)
- Immunodeficiencies with severe autoimmune complications and/or significantly diminished life expectancy
- Primary immunodeficiencies requiring lifelong treatment: Life expectancy is anticipated to be significantly shortened if the treatment is not available, 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 bone marrow transplant (with ongoing life-threatening complications)
- May be eligible with complicating comorbidities:
- Complications from immunosuppressive therapy

INFECTIOUS DISEASE

- HIV
- Congenital/Neonatal infections with sequelae, including but not limited to: CMV, Toxoplasmosis, HSV
- Infections with neurologic sequelae, including but not limited to: GBS meningitis with resultant developmental delay, S. pneumo meningitis with resultant deafness

INTENSIVE CARE

- Febrile Infection-Related Epilepsy Syndrome (FIRES)
- Hemophagocytic lymphohistiocytosis (HLH)
- Hypoxic brain injury

NEPHROLOGY

- Chronic Kidney disease, stage 3 with multiple acute illnesses/exacerbations in the last year requiring hospitalization
- Chronic Kidney disease, stage 4 or higher
- Dialysis dependent renal disease
- Kidney transplant (within one year of transplant)
- Kidney diseases dependent on long-term infusions and/or plasma exchange (e.g. atypical hemolytic uremic syndrome requiring chronic anti-complement therapy to stay in remission)
- Status post kidney transplant (with ongoing life-threatening complications)
- May be eligible with complicating comorbidities: Refractory nephrotic syndrome (e.g. multiple acute illnesses or relapses requiring infusion or medication and multiple immunosuppressive medications), Complications from immunosuppressive therapy

NEUROLOGY/NEUROSURGERY

- Neurodegenerative disease with significantly shortened life expectancy including: Leukodystrophy, Alpers disease, Leigh syndrome, Rett syndrome, Pelizeus Mertzbacher Syndrome, Neuronal brain iron accumulation (NBIA), Friedreich's ataxia
- Congenital neuromuscular disease with respiratory or cardiac complications including: Duchenne muscular dystrophy, Spinal muscular atrophy types 1 and 2, Myotonic Dystrophy
- Epilepsy/uncontrolled seizures that are: Intractable, Refractory, Treatment-resistant, Includes Lennox-Gastaut Syndrome
- Progressive cerebrovascular disease (e.g., stroke) with ongoing life-threatening complications: Moya Moya Disease, MELAS (mitochondrial encephalomyopathy, lactic acidosis, and stroke-like episodes), Osler-Weber-Rendu Syndrome, Fabry's Disease, CADASIL/CARASIL (cerebral autosomal dominant/recessive arteriopathy with subcortical infarcts and leukoencephalopathy), Sickle Cell Disease with Stroke
- Dysautonomia Conditions: Familial dysautonomia (Riley-Day), Traumatic Brain Injury with PAID (Paroxysmal Autonomic Instability with Dystonia), Cerebral Palsy with PAID, Spinal Cord Injury with Autonomic Dysreflexia
- Cerebral palsy with associated life-threatening complications e.g., intractable seizures, compromised respiratory failure.
- Profound neurodevelopmental delay with associated life-threatening comorbidities requiring significant and ongoing life-sustaining medical support.
- Traumatic brain or spinal cord injury with associated life-threatening comorbidities requiring significant and ongoing life-sustaining medical support.
- Traumatic brain or spinal cord injury with life-threatening complications, e.g. intractable seizures, compromised respiratory failure.
- Tuberous sclerosis, involving the brain or spinal cord

- ☐ May be eligible with complicating comorbidities: Arhinencephaly, Encephalopathy, Hydrocephalus, Megalencephaly, Myopathy, Neurofibromatosis, Spina bifida, Huntington's disease

ONCOLOGY

- ☐ Bone marrow/stem cell transplant (within one year of 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 a 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
- ☐ May be eligible with complicating comorbidities: Complications from immunosuppressive therapy

PULMONARY

- ☐ 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
- ☐ May be eligible with complicating comorbidities: Acute respiratory failure, Bronchopulmonary dysplasia, Tracheostomy with oxygen requirements (depending on underlying medical diagnosis or reason for tracheostomy), Chronic obstructive pulmonary disease, Primary ciliary dyskinesia, Severe asthma, Severe restrictive lung disease, Complications from immunosuppressive therapy

RHEUMATOLOGY

- ☐ 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, Granulomatosis, Microscopic polyangiitis, Polyangiitis, Polyarteritis nodosa, 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 of having continuing MAS issues
- ☐ May be eligible with complicating comorbidities: Complications from immunosuppressive therapy