SEVERE IMPAIRMENT DETERMINATION INTRODUCTION

A. Introduction

The purpose of the severe impairment determination process to is to establish consistent, objective criteria for determining if children meet the Adoption Assistance Program's (AAP) criteria of 'special needs.' This criterion is evaluated for adoptive children under the age of 2 for whom AAP is being applied, and for AAP recipients who are approaching the age of 18, and apply for continuation of subsidy beyond their 18th birthday.

A multi-step approach was developed to facilitate decision making, and help minimize the need for appeals and administrative reviews. The criteria and guidelines presented are based on definitions of severe impairments and disability used by the medical, psychiatric and educational communities. This document also includes some standards used by the Social Security Administration (SSA). The chart does not include every impairment that could be encountered during the determination process but covers a wide array of serious impairments that impact both children and adults.

Many conditions listed in this document have been obtained from the SSA and follow the diagnoses that would meet the SSA's criteria for disability. The SSA makes periodic changes to the list of impairments included on the list of 'Compassionate Allowances', and this process will be updated to incorporate these modifications as they occur.

B. Definitions and Requirements

Severe impairments are those that significantly limit an individual's mental or physical ability to function on a daily basis.

- **For individuals aged 18 and older**, severe impairment translates into an inability to work full-time or in a manner that is age appropriate for the individual.
- **For children under age 18**, severe impairment means inability to function age appropriately in everyday settings.

There are three critical elements when determining whether or not a condition meets the definition of severe impairment:

Diagnosis must be established by a licensed medical professional who has a treating relationship with the individual. **For these purposes, 'licensed medical professional' is defined as the child's**: • Physician, psychologist/psychiatrist, or nurse practitioner, or • Speech/language pathologist for speech/language disorders, or • Audiologist for hearing impairments
Duration must be present as identified by ongoing, long-term treatment.
Disability must be described by the presence of a medical condition that very seriously limits activities leading to inability to sustain work or function age appropriately.

In order to ensure that these elements are present for children approaching age 18, the '**Medical Information for Continuation of Adoption Assistance Benefits**' form (Medical Information Form) has been developed and must be used. The form is designed to elicit pertinent information about diagnosis, duration and disability from a licensed medical professional who has a treating relationship with the individual. In addition, the families will be asked to supply certain other records (school or medical) that they may easily have at their disposal. If families or other professionals in the child's life offer additional documentation about the child's mental or physical impairments, it will be considered in addition to, but not as a replacement for, documentation from the child's treating licensed medical professional. For children under age 18, medical documentation from a licensed physician, psychiatrist, psychologist, nurse practitioner or licensed medical professional (as defined above) must be provided indicating the child's diagnosis along with severity and duration of the diagnosis.

For some medical conditions, the documentation from the Medical Information Form and supplementary documentation will need to be utilized to make a determination about the severity of the child's impairment. In some cases, diagnosis alone of a particular impairment is sufficient for continuation of benefits. For other impairments, diagnosis, duration and impact on daily functioning must be considered in making the determination. A three level rating system will assist in determining whether or not a child can be in receipt or continue to receive benefits.

- **Level 1** – This level includes the most severe type of impairments. The severity expected with these impairments is extreme. These impairments are permanent or progressive in nature and not expected to improve over time. The criteria needed to establish this level are very straightforward and, in some instances, the diagnosis alone may be sufficient.

- **Level 2** – This level of impairment describes conditions less severe than Level 1. The level of severity must be sufficiently reflected by the medical information received to document that the impairment causes ongoing functional limitations. The functional limitations inherent in this level prevent the individual from being able to sustain work or being able to function appropriately for his/her age.

- **Level 3** – This level of impairment is still severe, but less so than that of Level 1 or 2. The severity indicated by this level is such that it requires pairing with other severe impairments at the same level or higher. The combination of impairments, when viewed in their totality, should equate to at least Level 2 severity. As with Level 2, there must be limitations in functioning appropriately for his/her age.

The Determination Process

The determination process consists of two steps that are designed to be followed in sequence. A determination made at Step 1 precludes the need to continue to Steps 2. The critical elements of diagnosis, duration, and disability have been built into each of the steps as necessary.

Step 1: Level 1 Impairment / Conditions and Compassionate Allowances[1]

Step 1: Level 1 Impairments / Conditions and Compassionate Allowances

Step 1 involves reviewing the charts 'Level 1 Severe Impairments' and 'Compassionate Allowances.' These charts are based on the Social Security Administration's initiative to expedite decision-making for the most severe impairments. These impairments are static or progressive, and not expected to improve over time.

While a diagnosis from the child's licensed medical professional is still required, the issues of duration and disability are implied once the diagnosis is verified. **This means that children who have one Level 1 diagnosis or a diagnosis from the 'Compassionate Allowances' list documented by their licensed medical professional are eligible for receipt or continuation of subsidy.**

Step 1: Level 1 Impairments / Conditions and Compassionate Allowances
Upon receipt of the completed medical form, review the charts **'Level 1 Severe Impairments' and 'Compassionate Allowances**' to determine if the child has a level 1 diagnosis on either list. In order to meet the criteria at this step, the diagnosis must be an exact match.
If the child has a level 1 diagnosis or a diagnosis on the Compassionate Allowances list, stop the review. Eligibility (special needs 'difficult to place' criterion for children under age 2) or continuation is established.
If there is not a diagnosis on the list that matches, continue to Step 2.

1 See 'Compassionate Allowances' chart attached after both Severe Impairment Charts

Step 1: Level 1 Severe Impairment Chart

TYPE OF IMPAIRMENT (Body System)	DIAGNOSIS	DISABILITY CRITERIA	SEVERITY LEVEL
BLOOD DISORDERS	**Blood disorder treated by bone marrow or stem cell transplant**	Disabled from the date of transplant	Level 1
	Coagulation disorders (Protein C or Protein S deficiencies, Factor V Leiden, Hemophilia, von Willebrand disease, Thrombocytopenia, acquired Hemophilia A)	Severe recurrent crises or episodes occurring within a 12-month period despite treatment documented by lab results, hospitalizations or need for transfusions	Level 1
	Disorders of bone marrow failure (Myelodysplastic syndromes, Granulocytopenia and Myelofibrosis)	Severe recurrent crises or episodes occurring within a 12-month period despite treatment documented by lab results, hospitalizations or need for transfusions	Level 1
	Hemolytic Anemias (Sickle Cell disease, Thalassemia, and their variants, Hereditary Spherocytosis, Acquired Anemias from Autoimmune disease or mechanical devices)	Severe recurrent crises or episodes occurring within a 12-month period despite treatment documented by lab results, hospitalizations or need for transfusions	Level 1
CANCERS AND TUMORS	**Acute Leukemia** (including all Lymphoblastic Lymphomas and Juvenile Chronic Myelogenous Leukemia (JCML))	Disabled for 24 months after diagnosis/relapse OR 12 months after bone marrow or stem cell transplant	Level 1
	Malignant Solid Tumors	Disabled at initial diagnosis or with recurrence of active disease	Level 1
	Neuroblastoma	With extension across the midline or distant metastases or recurrent or with onset at age 1 or older	Level 1
	Nervous System Cancers (primary central nervous system (CNS) – brain and spinal cord)	Any primary CNS cancer that is metastatic, progressive, or recurrent after initial therapy	Level 1
	Retinoblastoma	Extension beyond the orbit, persistent or recurrent after initial therapy or with regional or distant metastases	Level 1

Step 1: Level 1 Severe Impairment Chart

TYPE OF IMPAIRMENT (Body System)	DIAGNOSIS	DISABILITY CRITERIA	SEVERITY LEVEL
CARDIOVASCULAR IMPAIRMENTS	**Chronic heart failure**	Persistent arrhythmias at rest despite treatment or Persistent severe growth failure over 12-month period shown by repeated measurements of less than the 3rd percentile on standardized growth charts	Level 1
	Congenital heart disease	Cyanotic heart disease with persistent, chronic hypoxemia or need for surgical treatment in infancy, disabled up to 12 months post-surgery or symptomatic acyanotic heart disease interfering very seriously with daily functioning	Level 1
	Heart disease (due to any cause)	Need for transplant, disabled for at least 12 months	Level 1
	Rheumatic Heart disease	Persistent Rheumatic fever activity with significant murmurs, cardiac enlargement, or ventricular dysfunction	Level 1
ENDOCRINE DISORDERS	**Diabetes mellitus** (requiring injected insulin)	Uncontrolled despite medication, with recurrent acidotic episodes requiring hospitalization, or resulting in major organ dysfunction	Level 1
		Child under age 6 who requires daily insulin injections	Level 1
DIGESTIVE DISORDERS	**Crohn's disease**	Recurrent obstruction, anemia, perineal disease, or other chronic severe symptoms despite ongoing treatment	Level 1
	Extrahepatic biliary atresia	Confirmed by liver biopsy or intraoperative cholangiogram	Level 1

Step 1: Level 1 Severe Impairment Chart

TYPE OF IMPAIRMENT (Body System)	DIAGNOSIS	DISABILITY CRITERIA	SEVERITY LEVEL
DIGESTIVE DISORDERS, cont.	**Chronic liver disease**	Results in hepatic encephalopathy, hemorrhaging requiring transfusion, ascites, hydrothorax, spontaneous bacterial peritonitis, hepatorenal syndrome, hepatopulmonary syndrome, end stage liver disease or need for transplant	Level 1
	Gastrointestinal hemorrhaging (due to any cause)	Requiring repeated blood transfusions over 6-month period	Level 1
	Growth failure due to any digestive disorder	Chronic nutritional deficiency over 12-month period exhibited by anemia or low serum albumin and persistent severe growth failure over 12-month period shown by repeated measurements of less than the 3rd percentile on standardized growth chart	Level 1
	Inflammatory Bowel Disease (IBD)	Obstruction of stenotic areas of small intestine or colon requiring repeated hospitalizations for decompression or surgery over a 6-month period	Level 1
	Liver transplant	Disabled for at least 12 months post-surgery	Level 1
	Need for supplemental enteral feeding via gastrostomy, due to any cause	Dependent on daily enteral nutrition	Level 1
	Short bowel syndrome	Dependent on daily parenteral nutrition	Level 1

Step 1: Level 1 Severe Impairment Chart

TYPE OF IMPAIRMENT (Body System)	DIAGNOSIS	DISABILITY CRITERIA	SEVERITY LEVEL
GENITOURINARY DISORDERS	**Anasarca (generalized massive edema or swelling)**	Persistent for 90 days despite treatment	Level 1
	Chronic renal disease (Due to any cause)	Need for chronic dialysis and/or kidney transplant	Level 1
	Complications of Chronic Kidney disease	Requires repeated surgeries or hospitalizations as treatment over a 12-month period	Level 1
	Growth failure due to any chronic renal disease	Chronically abnormal serum creatinine and persistent severe growth failure over 12-month period shown by repeated measurements of less than the 3rd percentile on standardized growth charts	Level 1
	Kidney transplant	Disabled post-surgery	Level 1
HEARING AND SPEECH DISORDERS	**Deafness, due to any condition**	Totally deaf (not corrected by hearing aids), or pre-cochlear implants	Level 1
	Speech disorders	Loss of speech due to any cause with inability to produce, by any means, speech that can be heard, understood, or sustained	Level 1
	Post-cochlear implants	After age 5 or 1 year after surgery, whichever is later, with word recognition score of 60% or less	Level 1
IMMUNE SYSTEM DISORDERS	**HIV**	Manifested by severe bacterial, fungal, protozoan, or viral infections, malignant cancers, severe neurological complications, or severe immune suppression with growth failure shown by repeated measurements of less than the 3rd percentile on standardized growth charts	Level 1
	Inflammatory arthritis	Persistent inflammation or deformity of one or more peripheral joints (hands or feet) or ankylosing spondylitis	Level 1

Step 1: Level 1 Severe Impairment Chart

<table>
<tr><th>TYPE OF IMPAIRMENT
(Body System)</th><th>DIAGNOSIS</th><th>DISABILITY CRITERIA</th><th>SEVERITY LEVEL</th></tr>
<tr><td rowspan="3">IMMUNE SYSTEM DISORDERS, cont.</td><td>Polymyositis and dermatomyositis</td><td>Severe neurological complications that impair mobility or fine and gross movements, swallowing or respiration or sever diffuse calcinosis</td><td>Level 1</td></tr>
<tr><td>Systemic lupus erythematosus and systemic vasculitis</td><td>Involvement of two or more organs/body systems with severe ongoing symptoms (fatigue, fever, malaise, involuntary weight loss)</td><td>Level 1</td></tr>
<tr><td>Systemic sclerosis (scleroderma)</td><td>Involvement of two or more organs/body systems with severe ongoing symptoms (fatigue, fever, malaise, involuntary weight loss) or
Severe musculoskeletal complications that impair mobility or fine and gross movements or
Raynaud’s phenomenon with gangrene or ischemia</td><td>Level 1</td></tr>
<tr><td rowspan="2">LOW BIRTHWEIGHT AND FAILURE TO THRIVE</td><td>Low birth weight in infants from birth to age 1</td><td>Birth weight of less than 1200 grams (2lbs. 10oz.) or
Gestational age and birth weight in the chart
<table>
<tr><th>Gestational Age</th><th>Weight at Birth</th></tr>
<tr><td>37 – 40 weeks</td><td>Less than 2000 grams (4 lbs., 6 oz.)</td></tr>
<tr><td>36 weeks</td><td>1875 grams or less (4 lbs., 2 oz.)</td></tr>
<tr><td>35 weeks</td><td>1700 grams or less (3 lbs., 12 oz.)</td></tr>
<tr><td>34 weeks</td><td>1500 grams or less (3 lbs., 5 oz.)</td></tr>
<tr><td>33 weeks</td><td>1325 grams or less (2 lbs., 15 oz.)</td></tr>
</table></td><td>Level 1</td></tr>
<tr><td>Failure to Thrive in infants from birth to age 3</td><td>Severe persistent growth failure shown by repeated measurements of less than the 3rd percentile on standardized growth charts and developmental delays not more than 2/3 of the level expected for the child’s age or a score from a valid assessment at least 2 standard deviations below the mean</td><td>Level 1</td></tr>
</table>

Step 1: Level 1 Severe Impairment Chart

TYPE OF IMPAIRMENT (Body System)	DIAGNOSIS	DISABILITY CRITERIA	SEVERITY LEVEL
MENTAL DISORDERS	**Developmental Disorders**	Function is ½ or less of chronological age	Level 1
	Intellectual disability/Mental retardation	Extreme mental incapacity with dependence on others for personal needs and inability to follow directions or Valid IQ score of 59 or less	Level 1
	Intellectual disability / Mental retardation	Valid IQ score below 70	Level 1
MULTIPLE BODY SYSTEMS	**Non-mosaic Down Syndrome** (Chromosome 21 trisomy / translocation)	Confirmed by genetic testing	Level 1
	Catastrophic congenital abnormality or disease	Confirmed by genetic testing	Level 1
MUSCULOSKELETAL IMPAIRMENTS	**Permanent loss of function of lower or upper extremity, for any reason**	Inability to ambulate without assistive device or perform fine and gross movements	Level 1
NEUROLOGICAL IMPAIRMENTS	**Motor dysfunction, due to any cause**	Affecting 2 extremities with extreme limitations in functioning for fine and gross movements, or gait and station	Level 1
	Cerebral palsy	Affecting 2 extremities with extreme limitations in functioning for fine and gross movements, or gait and station	Level 1
	Seizure disorder due to any cause	One major motor episode/month, or 1 minor motor episode/week, despite medication with limited function	Level 1

Step 1: Level 1 Severe Impairment Chart

TYPE OF IMPAIRMENT (Body System)	DIAGNOSIS	DISABILITY CRITERIA	SEVERITY LEVEL
RESPIRATORY IMPAIRMENTS	**Lung transplant**	Disabled for at least 12 months post-surgery	Level 1
	Cystic fibrosis	Persistent symptoms (bilateral rales and rhonchi, pulmonary infection, or substantial reduction of breath sounds) despite treatment; recurrent episodes of bacterial infection, hemoptysis or respiratory failure; evidence of extensive lung disease; or severe growth impairment shown by repeated measurements of less than the 3rd percentile on standardized growth charts	Level 1
	Asthma	Frequent (once every 2 months or at least 6 times per year) attacks despite medication; prolonged use of corticosteroids, home nebulizer and frequent physician intervention	Level 1
	Growth failure due to any respiratory disorder	Hypoxemia requiring persistent oxygen supplementation and severe persistent growth failure shown by repeated measurements of less than the 3rd percentile on standardized growth charts	Level 1
SKIN DISORDERS	**Xeroderma Pigmentosum or other genetic photosensitivity disorder**	Inability to function outside of a highly protected environment	Level 1
	Skin lesions, due to any cause	Extensive skin lesions that persist despite treatment and severely restrict functioning	Level 1
VISION IMPAIRMENTS	**Blindness, due to any condition**	20/200 or less corrected vision in the better eye	Level 1
		Visual acuity recorded as CF (counts fingers), HM (hand movements), LP/LPO (light perception or light perception only), or NLP (no light perception) indicates an equivalent finding. Results of neuroimaging, electroretinogram or visual evoked response (VER) testing may also be used as equivalent.	Level 1

Step 2: Level 2 and 3 Severe Impairments

Step 2: Level 2 and 3 Severe Impairments:

The final step of the review process includes reviewing the chart **'Level 2 and 3 Severe Impairments'**, which includes a wide range of impairments, beyond Level 1, that have differing degrees of severity. Like step 1, this material is based on the disability criteria in Social Security federal rules.

The chart is divided into four columns:

- **Column 1 ('Type of Impairment')** indicates the overall category or type of impairment, and is arranged by the body system affected. All of the major body systems are covered, including mental disorders.
- **Column 2 ('Diagnosis')** lists the diagnosis or condition. The impairments/conditions listed are linked to the International Classification of Diseases – Clinical Modification (ICD-9-CM) and/or the Diagnostic and Statistical Manual of Mental Disorders (DSM). These two systems and the coding associated with them are commonly used by the medical/psychological communities. These codes are requested on the Medical Information Form that is completed by the individual's treating source.
- **Column 3 ('Disability Criteria')** provides a description of the criteria needed to meet the requirements of the particular diagnosis/condition. These criteria would be expected to be included in the information provided by the individual's treating source on the Medical Information Form, and/or reflected in any medical or school records or statements that might also be provided by the family or other professionals.
- **Column 4 ('Severity Level')** provides a level of impairment descriptor that ranges from most severe (Level 2) to less severe (Level 3).

Step 2: Level 2 and 3 Severe Impairments
Review the severe impairment chart to determine if information provided on the Medical Information Form from the child's licensed medical professional is equivalent to any diagnoses and descriptions contained in the chart.
Level 2 Severity: For receipt or continuation of subsidy, a child must have at least one, Level 2 diagnosis documented from a licensed medical professional, as well as clear indications that the impairments limit his/her mental or physical functioning on a daily basis. Indications of the impact on functioning will be reflected in the use and dosage of medications, frequency of visits to the doctor, duration of the impairment, and descriptions of how the impairment impacts the child's daily functioning. If the child meets both the diagnosis (Column 2) and description (Column 3) of a Level 2 impairment, he/she is eligible for receipt, or continuation of subsidy. **Level 3 Severity:** For receipt or continuation of subsidy, a child must have at least two Level 3 diagnoses documented from a licensed medical professional, as well as clear indications that the impairments limit his/her mental or physical functioning

on a daily basis. Similar to Level 2 diagnoses, indications of the impairment's impact on functioning will be reflected in the use and dosage of medications, frequency of visits to the doctor, duration of the impairment, and descriptions of how the impairment impacts the child's daily functioning. If the child meets both the diagnosis (Column 2) and description (Column 3) for two or more Level 3 impairments, he/she is eligible for receipt, or continuation of subsidy.

If the child does not have impairments equivalent to those on the Severe Impairment chart, subsidy eligibility / continuation has not been established.

Exceptions:
Remember that a child must meet the diagnosis of a severe impairment and it must impact their daily functioning as described in the chart. In some situations a child will have one or more impairments (diagnoses) that are listed on the Severe Impairment Chart, but the description of the condition does not impact daily functioning as significantly as required by the chart. In this case, the child can be considered for that condition, but at the next lower level. For example, a child has a diagnosis consistent with a Level 2 impairment, but it does not quite impact the child's daily functioning as severely as listed in Column 3 of the chart. The child would be considered to have a Level 3 impairment for that specific diagnosis, since he/she does not quite meet the severity required for Level 2, and the next lower level is a Level 3 impairment. Since the child is now a Level 3, there would need to be another Level 3 impairment or higher to make the child eligible for receipt or continuation of benefits. Note: this exception can only be used when the child's severity of functioning almost meets the criteria listed for a particular Level.

Example: Jane is diagnosed with asthma, and had a liver transplant 26 months ago.

According to the Severe Impairment Chart, Jane's liver transplant would indicate she has a Level 2 impairment for that condition, given the length of time that has passed since her surgery. Her doctor's description is that her body has accepted the organ very well, and though she is still being periodically monitored, it no longer has an impact on her day to day functioning. Because of the lack of day to day impact, Jane does not meet the criteria for a Level 2 impairment, but she can be identified as having a Level 3 impairment since she meets some of the criteria described for a Level 2 impairment, but not all.

Her asthma is a Level 3 impairment, given the frequency of her current attacks as described by her doctor. On its own, the severity of this condition is not enough to continue her subsidy beyond the age of 18. However, because the child now has two Level 3 diagnoses, continuation of subsidy is appropriate.

Step 2: Level 2 and 3 Severe Impairment Chart

TYPE OF IMPAIRMENT (Body System)	DIAGNOSIS	DISABILITY CRITERIA	SEVERITY LEVEL
CARDIOVASCULAR IMPAIRMENTS	**Congenital heart disease**	Cyanotic heart disease with persistent, chronic hypoxemia or need for surgical treatment in infancy, disabled post- surgery or symptomatic acyanotic heart disease interfering very seriously with daily functioning	13 months or more, post-surgery: Level 2
	Heart disease (Due to any cause)	Need for transplant, disabled for at least 12 months	13 months or more, post-surgery: Level 3
	Rheumatic Heart disease	Persistent Rheumatic fever activity with significant murmurs, cardiac enlargement, or ventricular dysfunction	19 months or more: Level 3
ENDOCRINE DISORDERS	**Diabetes mellitus** (requiring injected insulin)	Poor control despite medication without severe complications that limits functioning	Level 3
MENTAL DISORDERS	**Combination of mental disorders**	At least one of the following diagnoses: autism spectrum disorder, recurrent major depressive disorder, bipolar disorder, schizophrenia or other psychotic disorder, personality disorder, or amnestic disorder or traumatic brain injury	Level 2
		At least '2' of the following disorders: ADHD, body dysmorphic disorder, conduct disorder, conversion disorder, cyclothymic disorder, dysthymic disorder, eating disorder, elimination disorder, generalized anxiety disorder, learning disorder, language and speech disorder, mood disorder, obsessive-compulsive disorder, ODD, panic disorder, phobic disorder, PTSD, RAD, somatization disorder, substance abuse disorder, tic disorder This is NOT a comprehensive list.	Level 2
MUSCULOSKELETAL IMPAIRMENTS	**Fractures**	Non-union, with function not restored within 12 months	Level 2
	Burns, or soft tissue injury	Under surgical management, function not restored within 12 months	Level 2

Step 2: Level 2 and 3 Severe Impairment Chart

TYPE OF IMPAIRMENT (Body System)	DIAGNOSIS	DISABILITY CRITERIA	SEVERITY LEVEL
NEUROLOGICAL IMPAIRMENTS	**Seizure disorder due to any cause**	Less frequent episodes despite medication with limited function	Level 3
RESPIRATORY IMPAIRMENTS	**Asthma**	Less severe (requiring shorter courses of corticosteroids and less frequent home nebulizer use), and less frequent attacks, despite medication	Level 3

Compassionate Allowances

A
Acute Leukemia
Adrenal Cancer **With distant metastases or inoperable, unresectable or recurrent**
Adult Non-Hodgkin Lymphoma
Adult-Onset Huntington Disease
Aicardi-Goutieres Syndrome
Alexander Disease (ALX) **Neonatal & infantile**
Allan-Herndon-Dudley Syndrome
Alobar Holoprosencephaly
Alpers Disease
Alpha Mannosidosis **Type II / III**
Alstrom Syndrome
Alveolar Soft Part Sarcoma
Amegakaryocytic Thrombocytopenia
Amyotrophic Lateral Sclerosis (ALS)
Anaplastic Adrenal Cancer **With distant metastases or inoperable, unresectable or recurrent**
Angelman Syndrome
Aortic Atresia
Aplastic Anemia
Astrocytoma **Grade II and IV**
Ataxia Telangiectasia
B
Batten Disease
Beta Thalassemia Major
Bilateral Optic Atrophy **Infantile**
Bilateral Retinoblastoma

Bladder Cancer **With distant metastases or inoperable or unresectable**
Breast Cancer **With distant metastases or inoperable or unresectable**
C
Canavan Disease (CD)
Carcinoma of Unknown Primary Site
Cardiac Amyloidosis **All Types**
Caudal Regression Syndrome **Types III and IV**
CDKL5 Deficiency Disorder
Cerebro Oculo Facio Skeletal Syndrome (COFS)
Cerebrotendinous Xanthomatosis
Charlevoix-Saguenay Spastic Ataxia
Child Neuroblastoma – with distant metastases or recurrent
Child Lymphoma
Child Lympholastic Lymphoma
Chondrosarcoma **With multimodal therapy**
Choroid Plexus Carcinoma
Chronic Idiopathic Intestinal Pseudo Obstruction
CIC-rearranged Sarcoma
Coffin-Lowry Syndrome
Congenital Lymphedema
Congenital Myotonic Dystrophy
Congenital Zika Syndrome
Cornelia de Lange Syndrome – Classic Form
Corticobasal Degeneration
Creutzfeldt – Jakob Disease (CJD) **Adult**
Cri Du Chat Syndrome

D
Degos Disease
DeSanctis Cacchione Syndrome
Dravet Syndrome
E
Early-Onset Alzheimer's Disease
Edwards Syndrome **Trisomy 18**
Eisenmenger Syndrome
Endometrial Stromal Sarcoma
Endomyocardial Fibrosis
Ependymoblastoma **Child Brain Tumor**
Esophageal Cancer
Esthesioneuroblastoma
Ewing Sarcoma
F
Farber's Disease (FD) **Infantile**
Fatal Familial Insomnia
Fibrodysplasia Ossificans Progressiva
Follicular Dendritic Cell Sarcoma **Metastatic or recurrent**
Friedreichs Ataxia (FRDA)
Frontotemporal Dementia (FTD) **Picks Disease, Type A – Adult**
Fryns Syndrome
Fucosidosis **Type 1**
Fukuyama Congenital Muscular Dystrophy
Fulminant Giant Cell Myocarditis

G
Galactosialidosis Early and late infantile types
Gallbladder Cancer
Gaucher Disease (GD) Type 2
Giant Axonal Neuropathy
Glioblastoma Multiforme Brain Tumor
Glioma Grade III and IV
Glutaric Acidemia Type 2
H
Head and Neck Cancers With distant metastases or inoperable or unresectable
Heart Transplant Graft Failure
Heart Transplant Wait List 1A / 1B
Hemophagocytic Lymphohistiocytosis (HLH)
Hepatoblastoma
Hepatopulmonary Syndrome
Hepatorenal Syndrome
Histiocytosis Syndrome
Hoyeaal-Hreidarsson Syndrome
Hurler Syndrome Type IH & II, now known as MPS I
Hunter Syndrome Now known as MPS II
Hutchinson-Gilford Progeria Syndrome
Hydraencephaly
Hypocomplementemic Urticarial Vasculitis Syndrome
Hypophosphatasia Perinatal Lethal and Infantile Onset Types

Hypoplastic Left Heart Syndrome
I
I Cell Disease
Idiopathic Pulmonary Fibrosis
Infantile Free Sialic Acid Storage Disease
Infantile Neuroaxonal Dystrophy (INAD)
Infantile Neuronal Ceroid Lipofuscinoses
Inflammatory Breast Cancer (IBC)
Intracranial Hemangiopericytoma
J
Jervell and Lange-Nielson Syndrome
Joubert Syndrome
Junctional Epidermolysis Bullosa **Lethal Type**
Juvenile Onset Huntington Disease
K
Kidney Cancer **Inoperable or unresectable**
Krabbe Disease (KD) **Infantile**
Kufs Disease (KD) **Type A and B**
L
Large Intestine Cancer **With distant metastases or inoperable, unresectable or recurrent**
Late Infantile Neuronal Ceroid Lipofuscinoses
Leigh's Disease
Leiomyosarcoma
Leptomeningeal Carcinomatosis

Lesch-Nyhan Syndrome (LNS)
Lewy Body Dementia
Liposarcoma **Metastatic or recurrent**
Lissencephaly
Liver Cancer
Lowe Syndrome
Lymphomatoid Granulomatosis **Grade III**
M
Malignant Brain Stem Gliomas **Childhood**
Malignangt Ectomesenchymoma
Malignant Gastrointestinal Stromal Tumor
Malignant Germ Cell Tumor
Malignant Melanoma **With metastases**
Malignant Multiple Sclerosis
Malignant Renal Rhabdoid Tumor
Mantle Cell Lymphoma (MCL)
Maple Syrup Urine Disease
Marshall-Smith Syndrome
Mastocytosis **Type IV**
MECP 2 Duplication Syndrome
Medulloblastoma
Menkes Disease **Classic or Infantile Onset Form**
Merkel Cell Carcinoma **With metastasis**
Merosin Deficient Congenital Muscular Dystrophy
Metachromatic Leukodystrophy (MLD) **Late Infantile**

Mirtal Valve Atresia
Mixed Dementias
MPS I **Formerly known as Hurler Syndrome**
MPS II **Formerly known as Hunter Syndrome**
MPS III **Formerly known as Sanfilippo Syndrome**
Mucosal Melanoma
Multicentric Castleman Disease
Multiple System Atrophy
Myoclonic Epilepsy and Ragged Red Fibers Syndrome
N
Neonatal Adrenoleukodystrophy
Nephrogenic Systemic Fibrosis
NFU-1 Mitochondrial Disease
Niemann-Pick Disease (NPD) **Type A & C**
Nonketotic Hyperglycinemia
Non-Small Cell Lung Cancer **With metastases to or beyond the hilar nodes or inoperable, unresectable or recurrent**
O
Obliterative Bronchiolitis
Ohtahara Syndrome
Oligodendroglioma Brain Cancer **Grade III**
Ornithine Transcarbamylase Deficiency (OTC)
Orthochromatic Leukodystrophy **With Pigmented Glia**
Osteogenesis Imperfecta (OI) **Type II**

Osteosarcoma **Formerly known as Bone Cancer, with distant metastases or inoperable or unresectable**
Ovarian Cancer **With distant metastases or inoperable or unresectable**
P
Pallister-Killian Syndrome
Pancreatic Cancer
Paraneoplastic Pemphigus
Patau Syndrome **Trisomy 13**
Pearson Syndrome
Pelizaeus-Merzbacher Disease **Classic form**
Pelizaeus-Merzbacher Disease **Connatal form**
Peripheral Nerve Cancer **Metastatic or recurrent**
Peritoneal Mesothelioma
Peritoneal Mucinous Carcinomatosis
Perry Syndrome
Phelan-McDermid Syndrome
Pleural Mesothelioma
Pompe Disease **Infantile**
Primary Central Nervous System Lymphoma
Primary Effusion Lymphoma
Primary Progressive Aphasia
Progressive Bulbar Palsy
Progressive Multifocal Leukoencephalopathy
Progressive Supranuclear Palsy
Prostate Cancer **Hormone Refractory Disease – or with visceral metastases**

Pulmonary Atresia
Pulmonary Kaposi Sarcoma
R
Retinopathy of Prematurity **Stage V**
Rett Syndrome (RTT)
Revesz Syndrome
Rhabdomyosarcoma
Rhizomelic Chondrodysplasia Punctata
Roberts Syndrome
S
Salivary Cancers
Sandhoff Disease
Sanfilippo Syndrome **Now known as MPS III**
Schindler Disease **Type I**
Seckel Syndrome
Severe Combined Immunodeficiency **Childhood**
Single Ventricle
Sinonasal Cancer
Sjogren-Larsson Syndrome
Small Cell Cancer **Female Genital Tract, Large intestine, Ovary, Prostate, or Thymus**
Small Cell Lung Cancer
Small Intestine Cancer **With distant metastases or inoperable, unresectable or recurrent**
Smith Lemli Opitz Syndrome
Soft Tissue Sarcoma **With distant metastases or recurrent**

Spinal Muscular Atrophy (SMA) Types 0 and 1
Spinal Nerve Root Cancer Metastatic or recurrent
Spinocerebellar Ataxia
Stiff Person Syndrome
Stomach Cancer With distant metastases or inoperable, unresectable or recurrent
Subacute Sclerosis Panencephalitis
T
Tabes Dorsalis
Tay Sachs Disease
Thanatophoric Dysplasia Type 1
The ALS/Parkinsonism Dementia Complex
Thyroid Cancer
Transplant Coronary Artery Vasculopathy
Tricuspid Atresia
U
Ullrich Congenital Muscular Dystrophy
Ureter Cancer With distant or inoperable, unresectable or recurrent
Usher Syndrome Type 1
V
Ventricular Assist Device Recipient
W
Walker Warburg Syndrome
Wolf-Hirschhorn Syndrome
Wolman Disease
X

Xeroderma Pigmentosum
X-Linked Lymphoproliferative Disease
X-Linked Myotubular Myopathy
Z
Zellweger Syndrome