GENERAL INFORMATION

As you contact resources on behalf of families, you may become aware of updates or changes such as a different contact person, telephone number, or website. You may also discover that a resource is no longer available. Please notify the Managing Director of any changes so that this information can be shared with all Caseworkers, and this manual can be revised accordingly.

BEFORE CONTACTING A RESOURCE

Please be mindful of your working relationship with hospital social workers as you advocate for your families. Remember that it is ECF policy to regard the hospital person as the primary case manager, and they are often the referral source for our families. You should check with them before contacting other agencies for assistance, in order to prevent duplication of services and you should remain in contact with them regarding your work with families, providing the family has signed a release.

Over the years, this policy has evolved because we've learned that it is in the best interest of our families to do so. Working together, the ECF Caseworker and the hospital staff are able to provide a comprehensive package of support to those we serve. Of course, this does not apply if the child is no longer in active treatment or the hospital social worker is not involved.

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ABOUT CANCER

Cancer is actually a group of diseases, each with its own name, its own treatment and its own chances of control or cure. It occurs when a particular cell of group of cells begins to multiply and grow uncontrollably crowding out the normal cells. Cancer may take the form of leukemia, which develops from the white blood cells or solid tumors found in any part of the body. Despite considerable and continuing research, no one knows why children get cancer. Some common misconceptions about cancer are addressed below.

1.) As far as scientists have been able to determine, nothing you or your child did or didn’t do caused the disease. Cancer in children is still a largely unexplained disease and there is no evidence that you could have prevented it.
2.) Few cases of childhood cancer are due to genetic (inherited) factors.
3.) In almost all cases of childhood cancer, its appearance in one child does not mean that a brother or sister is more likely to develop it.
4.) Cancer is not contagious. It cannot be spread from person to person like a cold or from an animal to a person
5.) No food or food additive has been implicated as a cause of any childhood cancer.

LEUKEMIA

Leukemia is a cancer of the blood and develops in the bone marrow, the body tissue that produces red blood cells. The bone marrow is a jelly-like substance that fills the inside of the bones.

The bone marrow makes 3 kinds of cells”

1.) **Red Blood Cells** (erythrocytes) that give the blood its red color. These cells pick up oxygen and carry it to the tissues. They are also known as RBC’s.
2.) **Platelets** (thrombocytes) help stop bleeding if there is an injury.
3.) **White Blood Cells** (leukocytes) fight infections. They are also known as WBC’s. Leukemia develops in these cells. In leukemia, certain white blood cells escape the normal control mechanisms that direct their maturing. Instead of aging so they are able to assume certain functions, they remain young and continue to multiply. This can happen to any of the three main kinds of WBC’s:
   a. **Neutrophils**, which eat bacteria
   b. **Lymphocytes**, which make substances to fight bacteria
   c. **Monocytes**, which destroy foreign material

In speaking about Leukemia, “blast” is the short name used for lymphoblasts, the immature white blood cells. There are normal blasts and leukemia blasts. Normally, blasts compose <5% of the cells made by the bone marrow and grow to form mature white blood cells with certain typical features visible under the microscope. Leukemia blasts are abnormal because they remain immature and do not function like mature WBC’s. In many cases, they look different from normal blasts when viewed under the microscope.

When a large number of blasts appear in the bone marrow, several things happen. As the leukemic blast cells accumulate in the bone marrow, they begin to crowd out the normal blood cells that develop there. Eventually, they take up so much room that RBC’s platelets and normal WBC’s cannot be produced. When this happens, the young person develops symptoms indicating that normal blood cells are not being manufactured in adequate numbers:
1.) If RBC’s are crowded out by leukemic cells, the blood will look thin, which makes the patient look pale. The young person also may be tired because the blood cannot carry enough oxygen to the heart, lungs and muscles.

2.) If blood platelets are crowded out in the bone marrow, the young person may have bleeding problems and unusual bruising.

3.) If the normal, mature kind of ABC’ known a neutrophils are crowded out by the blasts, there will be no cells to combat bacteria and infections may occur.

In some cases, leukemic blasts may spill over from the bone marrow into the blood where they can be seen by microscopic examination. This may cause a rise in the number of white cells in the blood (the White Blood Cell Count). In other cases, only a few blasts appear in the blood and the white cell count does not change much. When leukemic blasts are present in the blood, they may be carried to other places in the body and enter various body organs. Sometimes they grow in these organs as well as in the bone marrow.

Leukemia is not just one disease. There is actually a type of leukemia for each of the three major kinds of WBC’s – neutrophils, lymphocytes and monocytes.

Leukemia in any one person can affect only one kind of blood cell. The most common kinds of leukemia are lymphocytic (also called lymphoblastic or lymphoid) and myelogenous (also called granulocytic, myelocytic, myelomonocytic, progranulocytic or erythroleukema) are very rare but still act much like the more common kinds.

If leukemia affects a young person quickly it is called “acute” because it comes on suddenly and progresses rapidly without treatment. Almost all childhood leukemias are acute but the disease is sometimes of the “chronic” type. In chronic leukemia the bone marrow is able to produce a good number of normal cells as well as leukemic cells so that compared to acute leukemia the actual disease course is milder for a period of time. Even without treatment, the disease usually progresses more slowly.

Acute lymphocytic leukemia (ALL) is commonly known as “childhood leukemia.” It is the most commonly occurring cancer in children. As its name suggests, it affects the lymphocytes. Most children are between 2 and 8 years old when diagnosed but the disease can occur in people in their twenties and thirties as well. For reasons yet to be understood, slightly more boys get ALL than girls and it occurs more frequently among white children than black children.

Acute myelogenous leukemia (AML) is also called acute granulocytic leukemia. It usually occurs in people over 25 but sometimes is found in teenagers and children. In AML, the leukemic blasts develop from the stem cells that would normally give rise to neutrophils. The characteristics of the blasts in AML are generally similar to those of acute lymphocytic leukemia but special tests can be done to help determine whether a leukemia is myelogenous or lymphocytic.

Chronic myelogenous leukemia (CML) is not common in children. CML’s distinguishing feature is the presence of very large numbers of immature neutrophil cells, which seem to mature more efficiently than blast cells. The progression of CML varies greatly, sometimes changing to a type of acute myelogenous leukemia.

Diagnosis of Leukemia requires blood tests and examination of the cells in the bone marrow because early symptoms can mimic many other diseases including mononucleosis, anemia arising from other causes, tonsillitis, rheumatic conditions, meningitis, mumps and other kinds of cancer.

In any acute leukemia, it is necessary to determine which type of WBC has become leukemic because treatment
and response to it are different for each kind. Usually, the type of leukemic cell involved can be determined from its appearance under the microscope but sometimes special tests of the chromosome and cell chemistry are needed for complete certainty. In rare instances, the cells are too young to be classified. Such cases are called acute stem cell leukemia or acute undifferentiated leukemia (AUL). Other tests such as X-rays and lung puncture may also be undertaken to determine if areas other than the bone marrow are involved.

The primary treatment for Leukemia is combination chemotherapy where two or more anticancer medications are used to control or eradicate the disease. Radiation, platelet and red cell transfusions, antibiotic therapy and occasionally surgery (for unusual complications) are also part of many treatment programs. In some forms of leukemia bone marrow transplantation is done.

**SOLID TUMORS**

The word tumor does not always imply cancer. Some tumors (collections of abnormally growing cells) are benign (not cancerous). In discussing tumors that are malignant (cancerous) however, the term solid tumor is used to distinguish between a localized mass of tissue and leukemia. (Leukemia is actually a type of tumor that takes on the fluid properties of the organ it affects – the blood).

Different kinds of solid tumors are named for the type of cells of which they are composed:

- **Sarcomas** are cancers arising from connective or supporting tissues such as bone or marrow.
- **Carcinomas** are cancers arising from the body’s glandular cells and epithelial cells, which line body tissues
- **Lymphomas** are cancers of the lymphoid organs such as the lymph nodes, spleen and thymus, which produce and store infections fighting cells. These cells also occur in almost all tissues of the body and lymphomas therefore may develop in a wide variety of organs. **Lymphomas** are cancers of the Lymphatic tissues, which make up the body’s lymphatic system. This system is a circulatory network of:
  - Vessels carrying lymph (an almost colorless fluid that arises from many body tissues).
  - Lymphoid Organs such as the lymph nodes, spleen and thymus that produce and store infection-fighting cells.
  - Certain parts of other organs such as the tonsils, stomach, small intestine and skin.

Lymphomas have been broadly divided into Hodgkin’s disease and non-Hodgkin’s lymphomas that include a number of diseases. Hodgkin’s disease tends to involve peripheral lymph nodes (those near the surface of the body) where the first sign of disease may be a painless swelling in the neck, armpit or groin. Hodgkin’s disease occurs most commonly in patients in their twenties and thirties and occasionally in adolescents. It is rare in younger children.

In children, non-Hodgkin’s lymphomas most frequently occur in the bowel particularly in the region adjacent to the appendix and in the upper midsection of the chest, a site where Hodgkin’s disease may also occur. An initial sign of disease in non-Hodgkin’s lymphoma may be abdominal pain or swelling, breathing difficulties and sometimes difficulty in swallowing or swelling of the face and neck.

Non-Hodgkin’s lymphoma may also occur in other organs including the liver, spleen, bone marrow, lymph nodes, central nervous system and bones. Lymphomas can be diagnosed definitively only through biopsy where a piece of tumor tissue is obtained surgically and examined under a microscope. Once the diagnosis is made, many tests must be done to determine the extent of the tumor including special X-rays, CT scans, isotope scans and ultrasound. Blood tests are also necessary.

In the case of Hodgkin’s disease, radiation therapy is highly effective for localized disease and has been the main form of treatment. However, it is believed that most lymphomas in young people are spread throughout the body
even though tumors may be detected in only one region. Because chemotherapy acts on cells through the body, it is the most important aspect of treatment. Surgery and radiation therapy are sometimes valuable in particular circumstances. Except in Hodgkin’s disease, treatment is usually given to prevent the spread of the disease to the brain and spinal column.

**RETINOBLASTOMA**
Retinoblastoma is a rare cancer of the eye. It may be hereditary and one third of the cases involve both eyes. Retinoblastoma often can be seen by looking at the young person’s eye but is usually diagnosed by an examination under general anesthesia using an ophthalmoscope, an instrument used in examining the interior of the eye. The disease tends to remain localized for long periods but in advanced stages, it can metastasize or spread to other parts of the body. X-rays, bone marrow examination, MRI and a bone scan can be done to check for metastases.

If diagnosed early, it is possible to destroy the tumor with radiation therapy and preserve normal visions. If the tumor is so large that there is no hope of maintaining useful vision using radiation, the eye is removed. In cases where both eyes are involved, an attempt is made to preserve vision in both eyes through treatments with radiation. When advance disease is found in both eyes an attempt is made to preserve vision in at least one eye. Whenever there is any possibility of useful vision, all efforts are made to preserve it. Chemotherapy, radiation or both may also be used to treat metastases.

**RHABDOMYOSARCOMA**
Rhabdomyosarcoma also called rhabdossarcoma is a type of soft tissue sarcoma arising from muscle cells. It occurs slightly more frequently in males and usually affects children between the ages of two and six. Although it can occur in any muscle tissue, it is generally found in the head and neck area, the pelvis or in the extremities.

Although rhabdomyosarcoma tends to grow and spread very rapidly, fortunately its symptoms are quite obvious compared to those of other forms of childhood cancer. A noticeable lump or swelling is present in almost all cases. Other symptoms depend on the location: if the growth is near the eyes for example. A vision problem may develop. If the neck is involved, there may be hoarseness or difficulty in swallowing. Definite diagnosis relies on biopsy. Evidence of tumor spread is sought with X-rays, tomograms, gallium scan, bone scan, liver scan and bone marrow examination. Other procedures such as lymphangiography, brain scan and spinal fluid examination may also be done depending on the tumor’s location.

Traditionally, surgery has been the primary treatment followed by intensive chemotherapy and radiation. However, if the tumor is so large that surgery presents a major risk to the patient or would result in serious disfigurement or physical impairment, then chemotherapy, radiation or both are used to reduce the tumor’s size until it can be removed more safely. In some cases, the cancer can be treated effectively with chemotherapy and radiation alone.

**OSTEOGENIC SARCOMA**
Osteogenic sarcoma also called osteosarcoma is the most common type of bone cancer in children. It arises in the ends of the bones. The bones most frequently involved are the large bones of the upper arm (humerus) and the leg (femur and tibia). Osteogenic sarcoma usually occurs between the ages of 10 and 25 and is more common among males than females.

Young people with this type of cancer generally complain of pain and swelling which they sometimes blame on an injury. Diagnosis can be difficult because the disease is easily confused with local infection, effects of injury, glandular deficiencies, arthritis, vitamin deficiencies and benign tumors.

Although osteogenic sarcoma may be suspected by the way the bone looks on W-rays, diagnosis can be confirmed
only by biopsy. Because the disease commonly spreads (metastasizes) to other parts of the body, especially the lungs, chest X-rays, lung tomograms, CT scans of the chest and an X-ray skeletal survey or bone scan may also be done before treatment.

Surgery (amputation or limb sparing) is the primary method of treatment followed by a course of chemotherapy using one or more anticancer drugs. A prostheses (artificial limb) and physical rehabilitation may be important parts of therapy.

**EWING’S SARCOMA**

Ewing’s Sarcoma differs from osteosarcoma in that it affects a different part of the bone – the bone shaft – and tends to be found in bones other than the long bones of the arm and leg such as the ribs. Like osteogenic sarcoma, it usually occurs between the ages of 10 and 25, is seen more often in males, and frequently spreads to other bones and the lungs.

**BRAIN TUMORS**

Brain tumors are classified and named for the type of tissue in which they develop. As a group, brain tumors are the second most common cancers of childhood. They may occur at any age, including early infancy and in adolescence, but are seen most often in children 5 to 10 years old.

Symptoms include seizures, morning headaches, vomiting, irritability, behavior problems, and changes in eating or sleeping habits, lethargy or clumsiness. Diagnosis is often difficult because these symptoms can and frequently do indicate any number of other problems wither physical or emotional. If a brain tumor is suspected, diagnostic tests usually include skill X-Rays, a brain scan, CT scans and magnetic resonance imaging (MRI).

Treatment depends on the type of brain tumor involved. For the most part, surgery, radiation or both are used. Anticancer drugs that can be given intravenously or orally and penetrate the brain and central nervous system are also used to treat brain tumors.

**NEUROBLATOMA**

Neuroblastoma arises from very young nerve cells that for unknown reasons develop abnormally. More than half of these tumors occur in the adrenal glands, which are located in the abdominal area near the kidneys. Neuroblastoma is found in children only with one-fourth of those affected showing initial symptoms during the first year of life and three-fourths before age 5.

Symptoms include a mass, listlessness, persistent diarrhea and pain in the abdomen or elsewhere. Again, these symptoms can point to other conditions. Diagnostic tests include and intravenous pyelogram (IVP), blood tests, ultrasound and other procedures depending on the site of the cancer. Because most children with this particular cancer secrete a substance that can be detected in the urine, urine tests may also be performed. The diagnosis may be further established by a biopsy for examination under an electron microscope.

Surgery is performed to remove as much of the cancerous growth as possible. If some remains after surgery, radiation may be used. Chemotherapy alone or combined with radiation can also be effective in treating the remaining tumor or in preventing metastases, the spread of the disease to another site.

**WILM’S TUMOR**

Wilms’s Tumor is a cancer that originates in the cells of the kidney. It occurs in children from infancy to age 15, is
rare in older patients and is very different from adult kidney cancers. It may rarely be hereditary and about 5% of the cases involve both kidneys.

Parents frequently bring Wilm’s Tumor to the attention of the doctor after they have noticed a slight swelling of lump in their child’s abdomen. Symptoms such as blood in the urine, weakness, fever, loss of appetite or abdominal pain may or may not be present.

Diagnosis begins with a physical examination and review of the child’s medical history. An IVP is the only X-Ray method often used. A special X-ray tomogram of the kidney (nephrotomography), CT scan or other specialized diagnostic X-ray tests may be ordered. Ultrasonic pictures and other types of examination may be ordered as needed.

Wilm’s Tumor is one of several cancers for which treatments have been developed combining surgery, radiation therapy and chemotherapy. The way in which these three methods will be used depends on the child’s medical history and general health and above all on the extent of the disease. Surgical treatment of Wilm’s Tumor (radical nephrectomy) involves removal of the diseased kidney and neighboring tissue and lymph nodes. Radiation therapy for example, is not often used in children under the age of 2 when their disease is localized. When radiation therapy is used after surgery, its purpose is to guard against recurrence of the cancer where the tumor has been removed. Chemotherapy is used to great virtually all cases of Wilm’s Tumor.
Note that resources highlighted in yellow are SOME of the groups that offer financial or scholarship assistance.

**Abbott Nutrition:** The manufacturer of Ensure will help families in need of their product but who are suffering financial hardship. Call customer service department at 800.227.5767. Ask for Patient Assistance Program.

**Alex’s Lemonade Stand Foundation:** Financial assistance to families who face the need to travel for childhood cancer treatment at select medical institutions across the US. Covered expenses include transportation, lodging, and meal accommodations. Application online at: [http://www.alexislemonade.org](http://www.alexislemonade.org)

**Allaire Community Farm:** [www.Allairecommunityfarm.org](http://www.Allairecommunityfarm.org)

**Supersibs:** now part of *Alex's Lemonade Stand*, sends supportive, helpful and informative age-appropriate information directly to young and teen siblings. [http://www.alexislemonade.org/campaign/supersibs/what-we-do](http://www.alexislemonade.org/campaign/supersibs/what-we-do)

**American Cancer Society:** Reimbursement from $150 - $300 per year for transportation. Volunteers drive patients to treatment. 1-(800) ACS-2345 is "Answer Line" and offers information on treatment, research, services and headlines news. Volunteer Parent-To-Parent support program. The main office is: American Cancer Society, NJ Division, Inc., 2600 US Highway #1, PO Box 6001, North Brunswick, NJ. (732)951-6308. For information about services in NJ and NY where their Hope Lodge is located: [http://www.cancer.org](http://www.cancer.org)

**American Childhood Cancer Organization:** Provide crucial support families need—financially, socially, and emotionally—through diagnosis, treatment, and well beyond. **FREE Books & Resources for Families of Children with Cancer is available.**

**Compassion Can’t Wait (Andre Sobel River of Life Foundation)** Emergency Assistance Program assists single parent families with urgent expenses to allow these caregivers to stay at their child’s bedside during catastrophic illness: 310-276-711 or [andreriveroflife.org](http://andreriveroflife.org). Please write “Every Day Needs Assistance” in the subject line. Caseworkers are welcome to inquire on behalf of families.

**Andrew McDonough B+ Foundation:** financial and emotional support to the family while they care for their child with cancer. The B+ Foundation is one of the largest providers of financial assistance to families of kids with cancer. Phone: (302)563-8389. Joe@BePositive.org or Carly@BePositive.org

**Angel Airlines:**

**Apple a Day:** Our mission is to bring joy into the lives of pediatric cancer patients though friendship, communication, sharing, and entertainment. When cancer treatment prevents or hinders normal childhood experiences and interaction, technology can become a welcomed bridge. This bridge also brings comfort, security, laughter, and a sense of normalcy in an otherwise scary and isolated battle. [https://appleaday.org/](https://appleaday.org/)

**Ashley Lauren Foundation:** The goal of The Ashley Lauren Foundation is to ease the journey when pediatric cancer is diagnosed by providing direct financial, material and emotional assistance, along with our many programs developed to bring smiles to the children. Address: 309 Morris Ave, Suite D, Spring Lake, NJ 07762. Phone: 732 414-1625, Fax: 732-414-1628, Email: info@ashleylaurenfoundation.org

**Association for Brain Tumor Research:** Research and information. 8550 W. Brynmawr Ave, Chicago, IL
Association of Cancer Online Resources: Collection of online communities designed to provide timely and accurate information in a supportive environment. 173 Duane Street, New York, New York. 212-226-5525 www.acor.org

Assurance Wireless: A free cell phone, along with 250 free minutes per month and discounted additional minutes, for NJ residents who receive SSI or Medicaid. There is no credit check. Application: call 1888-321-5880.

Aunt Bertha: Connecting People and Programs. www.auntbertha.com

A Week Away is a 501(c)(3) non-profit organization whose mission is to finance and coordinate respite weeks for individuals and their loved ones who are dealing with a life-threatening illness -- enabling them to find the peace and energy needed to continue fighting their disease. Mail: A Week Away c/o Disability Empowerment Center, 941 Wheatland Avenue Suite 201, Lancaster, PA 17603. Call; 717-742-5481, Email: info@aweekaway.org

The Beauty Foundation: We raise money to offset the expenses they incur, which are not covered under insurance such as childcare, household bills, transportation costs associated with treatment, and other needs from lifestyle changes caused by cancer. We also seek to help families through extremely difficult times with emotional support. We provide help during the holidays for those who are too ill or are unable to afford to have them. Additionally, we support the development of educational materials and provide support to local cancer centers. 788 Shrewsbury Avenue, #2197, Tinton Falls, NJ 07724 732.719.9909, 877.330.6649 (Fax) info@beautyfoundationnj.com

Benjamin's Hope for the Future: Provides financial assistance to pediatric cancer families, and a scholarship. www.bh4tf.org

Bereaved Parents of the USA: Self-help organization with “Local Chapter’s, publications, and newsletters. Contact National office for info: PO Box 622, St. Peters, MO. (708) 748-7866. www.bereavedparentsusa.org

Bianca’s Kids: A “wish-granting” organization for sick, needy, foster and other children. They serve families in NJ/PA/NY and they are based in Williamstown, NJ.

NJ State Board of Public Utilities: https://www.state.nj.us/bpu/assistance/programs/

Brain Tumor Foundation for Children: Provides informational support to families of children with brain and spinal cord tumors. www.braintumorkids.org

Brendan Borek High Tides Memorial Fund: Ongoing emotional and financial support for Cape May county families who have a child or young adult with cancer. (609) 967-0100. www.brendansfund.org

Bringing Hope Home:

Camp Clover: Offers traditional summer camp programs like swimming, sports, and arts and crafts, as well as educational and therapeutic activities designed to assist children in their grieving process. Activities are planned...
to foster coping skills that children can use throughout their lives. The camp is run by trained staff and volunteers and is funded strictly by donations. It also provides free bus transportation and lunch. To refer a child, volunteer or donate, call 973-379-8444.

**CancerCare, Inc.:** Free professional support services to anyone affected by cancer: people with cancer, caregivers, children, loved ones, and the bereaved. Programs including counseling, education, financial assistance and practical help are provided by trained oncology social workers and are. Assist Program provides limited financial assistance for homecare, childcare, transportation, medication and copays. Online support group for parents who have lost a child to cancer. Free services for professionals, including educational materials, distance learning programs (free CEUs for social workers), and professional consultation. Also offers a family patient resource room in the NJ office. Main Office: 141 Dayton Street, Ridgewood, NJ 07450, 201-444-6630 or 1-800-813-HOPE (4673). [www.cancercare.org](http://www.cancercare.org). Various Satellite Offices: call for info. Ridgewood office offers free wigs; call for appointment.

**Cancer Institute of NJ: [http://www.cinj.org/](http://www.cinj.org/)**

**Cancer Hope Network:** Trained Cancer Hope Network volunteers provide emotional support to the parents/family member of a child diagnosed with cancer. [www.cancerhopenetwork.org](http://www.cancerhopenetwork.org)

**The Cancer Project:** Free booklet available through website for parents of kids with (or without) cancer. “Nutrition for Kids: A Dietary Approach to Cancer Prevention” [www.cancerproject.org](http://www.cancerproject.org)

**CancerMatch:** Cancer support network, dating and social support for young adults and older. [www.cancermatch.com](http://www.cancermatch.com)

**Cancer Registry:** Keeps statistics on patients and cancer. Also provides information on any health issues through their health department on the website, [www.health.state.ny.us](http://www.health.state.ny.us)

**Cancer Support Community (The):** Offers a variety of programs and services for families, teens and kids. Each CSC Affiliate locations vary depending on the Affiliate. Search for the local program closest to your home and contact them directly. The Cancer Support Community asked about the possibility of working with ECF for a possible program or event; I am waiting for more information from them about this & their Program Director will be in touch shortly after this weekend. This could be a very positive opportunity for outreach for ECF as The Cancer Support Community is very well known & has close connections with a number of treatment centers. Here is their website for additional information. Main Sites Crossroads Drive, Bedminster, NJ. 908-658-5400: [https://cancersupportcnj.org/](https://cancersupportcnj.org/)

**Cancer Survivors’ Fund:** Provides college scholarships for survivors. Also provides assistance towards the cost of prosthetic and artificial limbs. Applications for both available at: [www.cancersurvivorsfund.org](http://www.cancersurvivorsfund.org)

**Candlelighters Childhood Cancer Foundation:** Information, advocacy, and self-help groups for parents of children with cancer in some areas. Provides professional assistance with insurance concerns. Will draft letter for family to send with declined bills, etc. Free quarterly newsletter and youth newsletter available through online PDF download. Mailing Address: 8323 Southwest Freeway, Suite 435, Houston, TX. 713-270-4700 [www.candle.org](http://www.candle.org)
**Catastrophic Illness in Children Relief Fund Commission**: Provides financial assistance for families whose children, 18 or younger, have experienced an illness or condition which is not otherwise covered by insurance or any State or Federal program. Medical expenses must exceed 15% of income. Contact Executive Director, (609) 292-0600 or 800-335-FUND. [www.NJCatastrophicfund.org](http://www.NJCatastrophicfund.org)

**Center for Hope Hospice & Palliative Care**: Provides hospice and respite services for families from Union, Middlesex, Essex and Somerset Counties. An interdisciplinary team provides physical, emotional and spiritual support to the patient and family members as one unit of care. Administrative Offices: Hope Center, 1900 Raritan Road, Scotch Plains, NJ 07076. (908) 889-7780. [www.centerforhope.com](http://www.centerforhope.com)

**Cerebral Palsy Foundation**: To provide those touched by cerebral palsy with the most compassionate voice, the most comprehensive resource, and the ultimate industry support network. (800) 692-4453.

**Chai Lifeline**: Jewish organization that provides the following support to children and families: transportation, cell phones, financial assistance, counseling, referrals, insurance claims, make-a-wish, educational support, respite program, library, newsletter, summer camp, recreational programs, and kosher meals. Caseworkers may request free publications. [www.chailifeline.org/NJ](http://www.chailifeline.org/NJ), 1-877-CHAI-LIFE. NJ office: 732-719-1700 or 800.882.0745.

**Children’s Brain Tumor Foundation**: A non-profit organization to improve the treatment, quality of life and the long term outlook for children with brain and spinal cord tumors through research, support, education, and advocacy to families and survivors. Toll-free information and support line; books; recreational events; program for survivors, and more. Free publication available: *A Resource Guide for Parents of Children with Brain and Spinal Cord Tumors*, now in its fourth edition. Co-sponsors conferences, teleconferences, and webinars for families, survivors and health care professionals. 274 Madison Avenue, Suite 1004, New York, NY 10016. 1-866-228-4673 or call Tracy Moore, Director of Support Services, at (212) 448-9494, or [www.cbtf.org](http://www.cbtf.org)

**Children's Cancer Fund (The)**: Financial aid for medical and non-medical needs of Ocean and Monmouth County families. Sponsors of Sunshine House in Point Pleasant Beach, which houses 4 families at a time for free, for up to a week. Offers counseling and support groups, and serves as an information center on treatment, research, nutritional information and community resources to all NJ families. 800 Route 88 #1, Point Pleasant Boro, NJ 732-899-9699

**Children’s Cancer Recovery Foundation**: The Foundation focuses on improving the mental, social and emotional well-being of families while helping to minimize the devastation that cancer can cause. The *Helping Hands Fund* provides a maximum of $250 per family, per year, for utility and rental fee bills. Child must be under the age of 18 and currently receiving active cancer treatment to qualify, and request must be made by Caseworker. Contact: 800.238.6479 or [childrenscancerrecovery.org](http://childrenscancerrecovery.org)

**Children’s Cause for Cancer Advocacy**: CCCA is the leading national advocacy organization working to achieve access to less toxic and more effective pediatric cancer therapies; to expand resources for research and specialized care; and to address the unique needs and challenges of childhood cancer survivors and their families. [www.childrenscause.org](http://www.childrenscause.org)
122 C Street, NW Suite 240 Washington, DC 20001 Phone: 202.304.1850 Or just fill out the simple form on line.

**Children's Hopes & Dreams Foundation**: A pen-pal program designated for children with chronic or life-
threatening illnesses, in addition to healthy children, to write to other children in a different state or out of the country. Children are matched by age, gender, and illnesses. Participation is free, and enrollment cards can be obtained by contacting the Pen-Pal Program at (973) 361-7366. Also sends Kids Kare packages: 280 Route 46, Dover, NJ 07801. http://www.hopesanddreamsfoundation.org/

**Children's Hospice International**: promotes the idea that critically ill children should have access to hospice/palliative care along with curative care from the time their life-threatening illness has been diagnosed. CHI has developed a treatment model (Children’s Program of All-Inclusive Coordinated Care, or Chi, which provides a blend of curative and hospice/palliative care services for critically ill children from the time of diagnosis) children. 500 Montgomery Street, Ste 400, Alexandria, VA 22314. 703-684-0330, 800-24-CHL. www.chionline.org

**Clayton Dabney Foundation for Kids with Cancer**: Foundation for Kids with Cancer provides needy families, with children in the last stages of terminal cancer, assistance in creating everlasting memories. Provides gifts, last wishes and financial assistance to families with children, 21 or younger, in the last stages of terminal cancer. $2000 cap. Contact them at: 214-361-2600 or access online at: www.claytondabney.org

**Comfort Zone**: 327 Turkey Top Road, Port Murray, NJ, 804-377-3430 Camp for children suffering any type of loss – under the age of 18. www.comfortzonecamp.org/

Comfort Zone provides therapeutic services to children that lose a loved one. Be A Vol

**Compassion Books**: Mail order collection of resources to help people through loss and grief. For catalogue write: 7036 State Hwy 80 South, Burnsville, NC 28714; or call: 1800-970-4220 or fax: 1-828-675-9687; or email www.compassionbooks.com_orders@web:compassionbooks.com

**Compassionate Friends (The)**: The Compassionate Friends provides highly personal comfort, hope, and support to every family experiencing the death of a child and helps others better assist the grieving family. Local chapter finder as well as publications, newsletters. PO Box 3696, Oak Brook, IL 60522. (630)990-0010, www.compassionatefriends.org

**Consumer Credit Counseling Service**: Our certified credit counselors will help you determine the best way to approach your financial situation and provide you the best options for managing your debt. Office in Cedar Knolls covers northern counties (973) 267-4324; office in Oakhurst covers Ocean County (732) 531-7272; office in Trenton covers Mercer County (609) 581-2455; office in Absecon Highlands covers Atlantic County: (800) 473-2227.

**Cooking for Kids with Cancer**: Chef Ryan Callahan author of *Cooking for Chemo…. And After*, created this new guide to help families with a crash course on food and flavor during and after your child’s cancer treatment. Book is $24.95 but also offers a website full of free information, how to guides, videos, and recipes. cookingforchemo.org
**Coping with a Child's Illness While You’re in Recovery**, [www.drugrehab.org/coping-childs-illness-recovery/](http://www.drugrehab.org/coping-childs-illness-recovery/)

**Cozies 4 Chemo**: To create hand-tied fleece cozies to provide warmth and comfort to cancer patients undergoing chemotherapy. To request a blanket Cozies4Chemo@comcast.net.

Cruise Against Cancer: For families affected by pediatric cancer. [Cruiseagainstcancer.com](http://Cruiseagainstcancer.com)

**David’s Dream and Believe Cancer Foundation**: 501(c)(3) nonprofit that raises funds to provide financial assistance, services a HOPE to families primarily in New Jersey, affected by a cancer diagnosis. (609) 489-0011, [Davidsdreamandbelieve.org](http://Davidsdreamandbelieve.org)

**Daxton’s Fish**: Our goal is to promote awareness, financially assist families touched by Neuroblastoma and raise money for pediatric cancer research. Simple application on line: [www.daxtonsfish.com/needassistance.htm](http://www.daxtonsfish.com/needassistance.htm)

**Dean Michael Clarizio Cancer Foundation**: [www.dmccf.com](http://www.dmccf.com)


**Family Reach Foundation**: Provides financial assistance to families of children or young adults with cancer. Primarily work with hospital social workers, but will consider requests from Caseworkers. Covered expenses include: transportation, palliative care, child care. For instructions on how to apply: Local office: 2001 Route 46, Suite 310, Parsippany, NJ 07054 Telephone: 973-394-1411 [www.familyreach.org](http://www.familyreach.org). **Make sure they know you are from ECF**.

**Famous Fone Friends**: Celebrity telephone calls to hospitalized or homebound children. Free to all families. (310) 204-5683. [www.famousfonefriends.org](http://www.famousfonefriends.org)

Fred’s Footsteps: [https://fredsfootsteps.org/our-program/](https://fredsfootsteps.org/our-program/)

**Fighting Children’s Cancer Foundation**: Financial assistance, with preference given to New Jersey families. Application form: 55 Lane Road, Suite 300 Fairfield, NJ 07004 (908) 429-2121 [http://fccf.info/](http://fccf.info/)

**Financial Success Center**: Monmouth Ocean County Families Tax Preparation for free: http://www.uwmoc.org/FSC

**First Hand Foundation**: Assists individual children who have clinical, health-related needs and no financial safety net to cover these expenses. By focusing on the individual child, First Hand reaches children and their families who would otherwise fall through the cracks of insurance coverage and state aid. [www.firsthandfoundation.org](http://www.firsthandfoundation.org)

**By email**: firsthandfoundation@cerner.com

**Friends Are By Your Side**: a consortium of Beauty industry Leaders, Salon Owners and Stylists committed to donating much needed hair replacement and styling services to women and children undergoing treatment for cancer. Also created ways to complete “a wish” request. Contact: 304 Hurffville Crosskeys Road, Sewell, NJ 08080 USA Phone: (856) 582-6600 Email: [www.friendsarebbyourside.com](http://www.friendsarebbyourside.com)

Free Dental Care: Free Dental Clinics. We provide full lists of free dental clinics that provide dental treatment for those in need. FreeDentalCare.us also provides full descriptions and phone numbers, addresses for the dental care clinics. [http://www.freedentalcare.us/](http://www.freedentalcare.us/)

**Friends of Karen:** Provides ongoing emotional support and financial assistance to families with a child who has a life-threatening illness. Financial assistance covers transportation, parking, meals for parents while their child is hospitalized, and living expenses for parents whose child is being treated at a distant location. Also provides food, clothing, and medical supplies. Manages individual funds, and will send information on fundraising to anyone interested in helping a family. 118 Titicus Road, PO Box 190, Purdys, NY 10578-0190. (914)277-4547. [www.friendsofkaren.org](http://www.friendsofkaren.org)

**Frances Foundation:** strives to alleviate a child’s pain and suffering with a special gift, a special gesture, or even a few special moments. The Foundation also provides financial assistance to impoverished families desperately needing help due to their child’s fight with cancer. Trips to Disney, Hospital party, Holiday gifts, Serve Thanksgiving Dinners, Sporting Event tickets, VIP Limo, Dinners, Shows and Concerts, Mother Day Flowers, Father Day Treats. Summer Picnic, Pool party. And….donations for Pediatric Cancer Research at St. Jude’s Children’s Hospital also supports research aimed to terminate childhood cancers. Contact: Bob Heugle; 732-219-7711; email: rheugle@byrnesoehrn.com; Mailing address: 8 Bryce Rd, Holdmdel, NJ 07733. Fighting Cancer, Inc. 733

**Gilda's Club of Northern and Southern New Jersey:** Support and cancer specific networking groups; exercise, art and nutrition workshops; educational lectures and social activities. 700 New Road, Linwood, NJ 609-926-2699, [www.gildasclubnnj.org](http://www.gildasclubnnj.org)

**Girl on the Go:** Private in-home wig consultations. 800 355-6976 [www.girlonthego.biz](http://www.girlonthego.biz)

**Give Kids a Smile Day:** With the support of the American Dental Association Foundation’s Give Kids A Smile program, launched nationally by the American Dental Association in 2003, more than five million underserved children have received free oral health services over the last 13 years. These free services are provided by approximately 10,000 dentists annually, along with 30,000 other dental team members. [https://www.adafoundation.org/en/give-kids-a-smile](https://www.adafoundation.org/en/give-kids-a-smile)

**Give Kids The World Village:** non-profit organization that exists only to fulfill the wishes of all children with life-threatening illnesses and their families from around the world to experience a memorable, joyful, cost-free visit to the Central Florida attractions, and to enjoy the magic of Give Kids The World Village for as long as there is a need. 800-995-KIDS (Tel) 407-396-1114 (Tel) ; [www.gktw.org](http://www.gktw.org)

**Glen Garcelone:** [http://www.glenngarcelonfoundation.org/index.html](http://www.glenngarcelonfoundation.org/index.html)

**Go 4 the Goal:** We provide financial support, developing and implementing unique hospital programs, funding innovative research, and granting personal wishes. Through our firsthand experience with pediatric cancer and our medical background, Go4theGoal provides the best practices to patients, their families, and the hospitals and staff that care for them. Address: 215 Cuthbert Blvd. Suite 150, Cherry Hill, NJ 08002 Email: go4thegoal.org

**Good Wishes:** provides free wraps or headscarves in children or adult sizes. Easy online application and contact info: [www.goodwishesscarves.org](http://www.goodwishesscarves.org)

**GriefSpeaks:** Presentations, Workshops, In-Service Training, Assemblies, Classroom Programs and Keynotes
on Topics Pertaining to Grief in the lives of Children, Teens and Adults Faced with Different Types of loss. www.griefspeaks.com

**Group Loop, The:** Site offers online support for teens with cancer. 1888-793-9355 www.grouploop.org

**Group Room, The:** Talk radio cancer support group. For more info. Go to www.thegrouproom.TV

**Hairprostheses.com:** Specialize in teenagers who have hair loss. "Certificate of Appreciation" issued by the "Memorial Sloan Kettering Cancer Center" to Rodolfo Valentin "for his support in the battle against cancer".

**Haven of Hope:** A free, 2-bedroom cottage retreat in Hope, NJ, for families caring for children with a life-limiting illness. Transportation and food are included. Maximum is 5 people. Limited to families in Northern New Jersey. http://www.hohfk.com/

**The Heart of South Jersey** (HSJ) is an inter-agency collaboration providing the southern New Jersey community with a quality support system for families experiencing difficulty achieving or maintaining self-sufficiency http://heartsj.org/

**Hello Grief:** Information and resources about grief for those who need support or are helping others cope. Community support online community of real people walking the walk, create interactive Memorial Walls, blog-style format, articles to suggested coping strategies from grief experts. Resources – We want to connect you with bereavement organizations in your area, so we provide a list by state, and nationally. www.hellogrief.org

**Holy Name Medical Center:** All programs are available for free to anyone impacted by Cancer including patients, caregivers, survivors and family members. We offer educational workshops, support groups, healthy lifestyle classes and social activities. Activities vary from month to month. Call 201-833-3392 or visit their website to learn more about Cancer Support Community and to register for any program you plan to attend.

**Hope Heals Support Groups:** **Cancer Support Group:** third Thurs of the Month, lower level. **Cancer Caregiver Support Group:** third Thursday of the month, upper level (elevator accessible). Both are located at Trinity Parish Center, 315 First Street, Westfield, NJ. Website: HTRCC.org

**Hospital Support Groups:** Contact your local hospital. Most hospitals and clinics that treat pediatric oncology offer support groups to parents and/or children (including some sibling groups). Some offer bereavement support groups as well. The hospital social worker can advise you.

**Imagine:** A year-round grief support center for children (3-18) and adults located in Westfield NJ and serving all surrounding communities, offering peer grief support programs for children and their parents dealing with the loss of a family member due to death. 908 264-3100  www.imaginenj.org

**Iron Matt Foundation:** Financial assistance for families whose child has brain or CNS cancer. Caseworker may apply on family’s behalf. PO box 836, Franklin Lakes, NJ 07417. 201-410-2751 www.ironmatt.org

**Jay Fund:** https://www.google.com/search?q=jay+fund&ie=UTF-8&oe=UTF-8&hl=en-us&client=safari
**Jenna’s Rainbow Foundation:** Provides funding for children with brain and spinal cord tumors. Sends kids to Camp Sunshine in Maine for one week. Hosts Jenna’s Corner, and online support group. 201-541-7590 jennasrainbow.org

**Jason’s Dreams for Kids:** fulfill the dreams of children diagnosis with life-threatening illnesses through a variety of fundraisers, corporate and personal donations. For more information: jasonsdreams@comcast.net.

**JCP Childrens Foundation:** [http://www.jpcf.org/](http://www.jpcf.org/)

**Jeremy Fund:** Financial assistance to families whose children are oncology patients at the Children's Hospital of Philadelphia. Write to them at 234 Sullivan Way, Ewing, NJ 08628 or e-mail them on their website. [www.thejeremyfund.org](http://www.thejeremyfund.org)

**Julia's Butterfly Foundation:** Assistance to terminally and chronically ill children in the tri-state area (NY/NJ/CT). Payment made directly to the provider. All applications must be completed in full and be returned via email to info@juliasbutterflyfoundation.org or returned in the mail to: Julia’s Butterfly Foundation, 637 Wyckoff Avenue, Suite 285, Wyckoff, New Jersey 07481. 201-675-9961 Download application online: [www.juliasbutterflyfoundation.org](http://www.juliasbutterflyfoundation.org), or email info@juliasbutterflyfoundation.org

**Karen DeLisle Memorial Scholarship Fund:** The "Sigh-of-Relief" Scholarship is awarded to need-based college students experiencing financial difficulties resulting from the cancer-related illness or death of an immediate family member. Applicants must be degree-seeking college or trade school students from New Jersey. Up to $5000/year and can be awarded for multiple years and to multiple siblings. Online application (must mention ECF and Caseworker’s name): [www.kdmsf.org](http://www.kdmsf.org)

**Kelly Ann Dolan Memorial Fund:** Assists families who have a child that is critically, chronically, or terminally ill, with reimbursement for an uninsured, non-medical expense. They also provide respite programs, and non-cash items to families in Pennsylvania, New Jersey, and Delaware; we advocate for and provide education and information to families nationwide. Application on line or call 215-643-0763. [dolanfund.org](http://dolanfund.org)

**Kick Cancer Overboard:** Free cruises for people that have been affected by cancer. Mailing address: Drs. James Parker Blvd Suite 104 | Red Bank, NJ 07701 | (732) 758-1990 kickcanceroverboard.com/

**Kids Need More:** Charitable organization dedicated to enhancing the lives of children, families & young adults coping with cancer and life-threatening illness. [https://kidsneedmore.org/](https://kidsneedmore.org/)

**Kids Wish Network:** Kids Wish Network is a charitable organization dedicated to infusing hope, creating happy memories, and improving the quality of life for children having experienced life-altering situations. Kids Wish Network assists children and their families through several key programs. They are especially proud of its Guardian Angel Fund. 1-888-918-9004, 4060 Louis Ave., Holiday, Florida 34691.

**Kisses for Kyle:** offers a variety of services to families fighting childhood cancer in the Delaware Valley. Our main goal is to help with direct financial assistance, as well as provide gifts and donate items to comfort the entire family, not just the child battling cancer. These gifts are provided throughout the year, as well as through our annual Holiday Wish List. [http://www.kissesforkyle.org/](http://www.kissesforkyle.org/)

**Lasting Connections, Inc.:** Helps families of terminally ill patients pay telephone bills. Applications considered by the 20th of each month. Maximum payment is $600.00. 277 Fairfield Rd., Ste. 132, Fairfield, NJ
Leukemia & Lymphoma Society: Improve the quality of life of patients and their families and ensure access to treatments for blood cancer patients. [www.lls.org](http://www.lls.org) Look under Resources for more specific information. They are also looking to reopen their Patient Aid service to provide some financial reimbursement to patients; more information will be available on their website [www.lls.org](http://www.lls.org) or by calling their Information Resource Center [IRC]: 1-800-955-4572 or emailing them at [http://www.lls.org/content/contact-us?UID=LLS-26-756&amp;url=http://www.lls.org/aboutlls/contactus/contactus_form/&pageTrackerID=UA-225158-16&amp;domain=.lls.org](http://www.lls.org/content/contact-us?UID=LLS-26-756-url=http://www.lls.org/aboutlls/contactus/contactus_form/&pageTrackerID=UA-225158-16-domain=.lls.org)

Lighthouse Family Retreat: faith based retreat for families. [https://www.lighthousefamilyretreat.org](https://www.lighthousefamilyretreat.org) The Low Income Home Energy Assistance Program (LIHEAP): helps keep families safe and healthy through initiatives that assist families with energy costs. Get information on how and where to apply for energy assistance by visiting website: [www.acf.hhs.gov/oes/programs/liheap](http://www.acf.hhs.gov/oes/programs/liheap)

Lions Clubs: Hearing Aids and Glasses. Contact your local Regional Director for this resource.

Locks of Love: Devoted to helping every child suffering from medical hair loss by providing hairpieces. Mailing address: 234 Southern Blvd, West Palm Beach, FL 33405. 1-888-896-1588. [www.locksoflove.org](http://www.locksoflove.org)

Love Clara: The mission of “Love Clara” is to “…provide families with financial support and "love" packages to help ease the burden as they walk the darkest days mourning a beloved child. When a family experiences their darkest hour, Love Clara seeks to offer not only financial support to offset some of the funeral and burial costs, but also emotional support through "love" baskets from a family who understands and empathizes with their depths of pain and loss.”

Lunch Break: [www.lunchbreak.org](http://www.lunchbreak.org)

Merlin’s Magic Wand: We make magic by arranging magical days out at Merlin Entertainments attractions, such as Legoland Resorts theme parks, Sea life Centers and Madam Tussauds. Visit [www.merlinsmagicwand.org/usa](http://www.merlinsmagicwand.org/usa) for more info.

Mesothelioma Cancer Alliance Scholarship: This opportunity is offered twice each year for college students who have been diagnosed with any type of cancer and their siblings to apply for a $4000 scholarship: [www.mesothelioma.com/scholarship/](http://www.mesothelioma.com/scholarship/)

Metheny School: Serves students with a diverse range of medically complex developmental disabilities. Through our fully NJ private integrated program of special education combined with therapeutic, social, and health services, we are dedicated to ensuring each child reach the maximum potential for learning and independence. 908-234-0011 Email info@matheny.org [www.Matheny.org](http://www.Matheny.org)

Miracle for Mateo: Miracle for Mateo provides financial support for families with dependent children who: have complex congenital heart disease or another life threatening illness, and are struggling through a lengthy hospitalization, are waiting for transplant, or who are living at home on hospice care. They accept applications monthly and review completed applications on the third Tuesday of each month. Miracle for Mateo offers support to families who have a child receiving medical treatment in the Tri-State area (NJ, DE and PA) by providing funds for: hospital cafeteria meals, utility bills, living expenses, gas and travel expenses, and/or a wristband bracelet fundraiser.
**Mission4Maureen**: provides financial assistance to families who are burdened by the staggering cost of brain cancer treatment. Financial aid is available for medical bills as well as childcare, housing payments, utility bills, transportation, medication and other areas of assistance. To apply for aid, download and complete the “Financial Assistance Application” in its entirety and submit as instructed. [www.mission4maureen.org](http://www.mission4maureen.org)

**Mya Lin Terry Foundation**: Create awareness, generate resources, identify causes, support new treatment options leading to cures, and eliminate national and critical drug shortages affecting pediatric cancer patients. 732-517-0697 kellylynnterry@msn.com

**National Brain Tumor Foundation**: Educational materials, newsletter, toll-free information line, brain tumor support groups, national and regional conferences, and support of research. 55 Chapel Street, Suite 200, Newton, MA. Phone: 617 924 9997 [www.braintumor.org](http://www.braintumor.org)

**National Cancer Institute**: Federal agency providing free cancer information: brochures, coloring books, nutrition books, etc. Part of the NIH. Cancer Information Service hotline: 1-(800) 4-CANCER. Office of Cancer Communications provides materials used in patient and public education. Write: National Cancer Institute, Public Inquiries Office, BG 9609 MSC 9760, 9609 Medical Center Drive, Bethesda, MD 20892 [www.cancer.gov](http://www.cancer.gov)

**National Children's Cancer Society, Inc. (The)**: Free publications that provide survivors and parents with information on cancer, healthy lifestyle habits, and survivorship. Scholarships for survivors from their Beyond the Cure program. Bone Marrow Transplant and Pediatric Oncology Programs offer financial assistance for various medical expenses. Requires application. Advocacy with insurance companies, hospitals, etc. as well as provision of other resources in the community. Summer camp. 314-241-1600 500 North Broadway, Suite 1850, Saint Louis, MO 63101. [www.thenccs.org](http://www.thenccs.org)

**National Coalition for Cancer Survivorship**: Promotes awareness of and will help families deal with issues of insurance, employment rights, and communicating with medical personnel. Has database of support groups throughout the nation. Advocates for changes in how the nation researches, regulates, finances and delivers quality cancer care. Empowers cancer survivors through its publications and programs, which provide tools for self-advocacy. Convenes other cancer organizations to address nationwide public policy issues affecting cancer survivors. [www.canceradvocacy.org](http://www.canceradvocacy.org)

**National Institute of Health (NIH)**: See National Cancer Institute. NIH will sometimes give second opinions free of charge. 301-496-4000. [www.nih.gov](http://www.nih.gov)

**National Leukemia Association (Children's Leukemia Research)**: Co-Pay Assistance Programs help with leukemia-related medical bills that are listed under our Covered Treatments and Services. Upon approval of each claim, payment will be made to the patient, guardian or medical provider. There are caps in some categories. Unusual and extraordinary expenses will be considered based upon need and availability of funds. Application form located under “Home”, Patient Aid Program, form must be signed by physician. 585 Stewart Avenue, Suite 18, Garden City, NY 11530. (516) 222-1944. [www.childrensleukemia.org](http://www.childrensleukemia.org)

**NetWish.org:** Financial assistance in the form of bill payments and gift cards given anonymously to those who can demonstrate need. The maximum request for aid is $200.00. Fill out form online [www.netwish.org](http://www.netwish.org)

**Neward Child Care Map – Programs for Parents:** [Newarkchildcaremap.com](http://newarkchildcaremap.com)

**New Jersey American Water:** Provides low-income assistance programs. 1-800-272-1325, or [www.newjerseyamwater.com](http://www.newjerseyamwater.com)

**New Jersey Anti-hunger Coalition (NJAHC):** Formally the *Statewide Emergency Food and Anti-Hunger Network (SEFAN):* A project for the Center for Food Action. NJAHC educates the public and policy makers about hunger in NJ and advocates for responsible policies and improvements to programs that help those in need such as Emergency food, supplemental nutrition assistance programs, school breakfast, food stamps, after school programs and women, infants and children(WIC). There is a list on the website of pantries by county [cfanj.org/njahc-home](http://cfanj.org/njahc-home/)


**New Jersey Department of Health:** See website for specific programs available. [www.state.nj.us/health](http://www.state.nj.us/health)

**New Jersey Family Care:** Federal and state funded health insurance program created to help New Jersey's uninsured children and certain low-income parents and guardians have affordable health coverage. The entire application process can be completed by mail or online: [www.njfamilycare.org](http://www.njfamilycare.org) or 1-800-701-0710.

**New Jersey Hospice Organization:** Central number for the hospice organizations in New Jersey. Hospice care is to enhance the quality of life for patient and family and allow patients to spend their remaining time in their home. Hospice provides comfort when cure is no longer possible or curative treatment is no longer desired. Focuses on quality of life rather than rehabilitation and cure. Also provides bereavement support. [http://www.homecarenj.org/](http://www.homecarenj.org/)

**New Jersey Insurance Department - Life and Health Insurance Section:** Provides information, answers questions, and takes complaints concerning insurance. 201 E. State Street, Trenton, NJ 08625. 1-800-446-7467 or (609) 292-8863. [http://www.nj.gov/dobi/division Insurance/index.htm](http://www.nj.gov/dobi/divisionInsurance/index.htm)

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**The New Jersey Pediatric Patient’s Charitable Trust Fund, Inc.:** Provides funding for the acquisition of equipment and services for medically fragile children in the following counties: Atlantic, Burlington, Camden, Cape May, Cumberland, Gloucester, and Salem. Phone 856-346-3300 ex 178 [www.sjkidstrust.com](http://www.sjkidstrust.com)

**New Jersey Self-Help Clearinghouse:** Provides referrals to support groups and provides information to start up new support groups. 1-800-367-6274, [www.njgroups.org](http://www.njgroups.org)

**New Jersey SHARES:** provides assistance to individuals and families in need of help meeting their energy and
utility burden. Help sites available in all counties. A list of other areas of assistance is also available. Visit www.njshares.org for complete guide. 1-866-NJ SHARES for local agency information.

New Jersey State Department of Health Special Child Health and Early Intervention Services Program: County Case Management units provide early intervention, educational issues, Medicaid assistance, medical equipment, and other services for children up to age 21. Listings by County available online as well as important phone number:  www.state.nj.us/health/fhs/sch/index.shtml

This resource is available in most communities and can help families with supportive services and possible emergency financial help as discovered by Jennifer.  https://www.nj.gov/dcf/families/support/success/

Noah’s Gifts Foundation: All teens age 13-19 are encouraged to apply. Noah’s Gift Grants are awarded to deserving young people so that they may pursue their dream or an extraordinary experience. It will not fund more than 80% of the costs associated with your extraordinary experience. A breakdown of the costs associated, as well as a brochure or flier of your experience must be attached. Download application at: www.noahsgifts.org.

Ocean of Love: Offers Ocean County families’ ongoing emotional and financial support, concrete services, and support groups. 1709 Hwy 37 East, Toms River, NJ 08753. Telephone: 732-270-3500 oceanoflove.org.

Parental Rights in Special Education: Booklet. New Jersey State Department of Education, PO Box 500, Trenton, NJ 08625. 609-292-0147 PDF download: http://www.state.nj.us/education/specialed/form/

Pajama Program: pajamaprogram.org

Patient Advocate Foundation: A complete listing of NJ-based resources offering assistance to patients with specific issues they are facing with their insurer, employer and/or creditor regarding insurance, job retention and/or debt crisis matters relative to their diagnosis of life threatening or debilitating diseases. Also offer a Scholarships for Survivors program. 800-532-5274 Apply online at: www.patientadvocate.org

The Paul Jackson Fund: A resource of last resort for individuals and families facing a financial crisis due to a debilitating long-term illness or disability. The Fund provides grants to qualifying individuals in the tri-state area (NY, NJ, & CT) for health-related needs as well as for family and household needs. Applications are accepted and evaluated year-round by The Fund. Grants are awarded on as-needed basis. P.O. Box 2014, Westfield, NJ 07091 908-233-6110 phone, Email: info@pauljacksonfund.org, www.pauljacksonfund.org.

Pediatric Brain Tumor Foundation of the U.S.: Family support programs, educational materials, support a national database on all primary brain tumors, aid in the early detection and treatment of this disease and provide online family support group. Scholarship program for survivors. Online support info: 1800-253-6530 or email www.curethe kids.org


Pennies from Heaven; CALEB’s Foundation: assisting families who have a critically ill child fighting for their life. We provide financial support so parents do not have to leave their sick child’s bedside. Our help comes by way of covering rent or mortgage payments, electric or medical bills, groceries, transportation and more. No
parent should have to prioritize a payment or job before the care of their sick child. Check out website for qualifications and applications as well as other programs. Contact Info: 104 Tink Wig Ct. Hawley PA 18428, 866-297-1321 (Fax) or email: calebspennies18@gmail.com


**PSE&G Payment Assistance Outreach**: Centers located in most counties to help low-income families with winter heating bills. Renters may qualify as well. Can assist with emergency heating system services and emergency financial assistance during a specific time of the year. You must apply from November 1st to March 31st. 1-800-510-3102. [www.pseg.com](http://www.pseg.com)


**Rainbow Foundation**: Provides assistance to children and their family! We’ve paid hospital and medical bills, arranged transportation for both extraordinary surgeries and ongoing treatments, donated wheelchairs and prosthetic devices, bought air conditioners for children with Cystic Fibrosis, and even made grants to families in dire need.
Phone: 732 671-4343 Email: info@kissesforkyle.org

**Re-Mission**: Free download of a video game designed to help young cancer patients take their medications. Players blast cancer cells and control side effects, and winning the game requires taking chemotherapy drugs and antibiotics, using relaxation techniques, eating food, and keeping up with other types of self-care. [www.re-mission.net](http://www.re-mission.net)

**Richard D. Frisbee Foundation (The)**: Support basic and clinical research to further understanding and treat childhood and adult cancers and related bone marrow diseases. Advance the application of bone marrow and stem cell transplantation. Establish support systems for patients and their families during treatment. Provide ongoing educational programs for healthcare professionals. Family support groups of various types also available. [www.frisbeefoundation.org](http://www.frisbeefoundation.org)

**Ronald McDonald House Charities**: Provides a “home-away-from-home” for families of seriously ill children who are receiving treatment at nearby hospitals at Ronald McDonald House. Families are asked to make a donation ranging from $5 to $25 per day; if that isn’t possible, their stay is free. Currently they have four NJ sites: Long Branch, Roseland, New Brunswick, and Camden. They also have mobile units and family rooms at certain hospitals. Offer scholarships to students from disadvantaged communities who face limited access to educational and career opportunities. [www.rmhc.org](http://www.rmhc.org)

**Samantha Fund**: To help families after they have learned their child has been diagnosed with a life altering illness. Financial assistance may go towards costly medical bills or other family bills, help supplement a parent’s income when a leave of absence occurs, or the cost of a hotel stay during hospital treatments: (201) 874-8072 or info@samanthafund.com.

**The SAMFund**: provides grants and scholarships to young adult survivors to help supplement the money that they and their families had lost during treatment, and pay for specific transitional issues, such as education, living, job search and lingering medical expenses. Applicant must 17–35 years old, a US resident, and finished with treatment. [www.thesamfund.org](http://www.thesamfund.org), info@thesamfund.org, or 617-938-3484
Shade of a cure: A team of women dedicated to awareness, prevention, and mostly finding a cure for all different types of cancer. Find out more about their programs at www.facebook.com/Shadesofacure

Sing me a Story Foundation: ECF children can write and illustrate stories about anything they want. Those stories are distributed to songwriters who turn them into songs, record them and send them back to the children by uploading them back to the site. SMAS Jukebox Campaigns are then created for each song uploaded in an effort to raise money for the Partnering Organizations and Sing Me a Story. https://singmeastory.org Please go through Managing Director of ECF who has an account with them online or call 615-873-0804.

PUBLIC NOTICE The New Jersey Department of Community Affairs (DCA), Division of Housing and Community Resources (DHCR) will be accepting pre-applications online at: www.WaitlistCheck.com/NJ559 for the Housing Choice Voucher (HCV) Program waiting list in all twenty-one (21) New Jersey counties.

Smiles for Sophie: Provide financial and emotional support to families burdened by pediatric brain tumors as well as promote a global awareness. Financial support to St. Jude, where Sophie was treated, and to other viable organizations committed to the treatment and cure of pediatric brain cancer. Request a Grant application by applying online.request an application in writing, by mailing your request to Smiles For Sophie Forever 31722 Leeward Ct. Avon Lake, OH 44012. www.smilesforsophieforever.org

Supplemental Nutrition Assistance Program: https://www.fns.usda.gov/snap/supplemental-nutrition-assistance-program-snap

Songs of Love Foundation: A nonprofit organization dedicated to providing personalized uplifting songs, free of charge, for children and teens currently facing tough medical, physical or emotional challenges. Song requests can be filled in as little as two days, in an emergency. A form, available on the website, must be filled in completely and legibly. www.songsoflove.org or call: 1.800.960.SONG.

Starlight-Starbright Children’s Foundation: We fund critical needs expressed by more than 600 community partners including hospitals, specialty clinics and camps, respite houses and hospices in the United States and Puerto Rico that collectively support more than 27 million visits every year. Starlight supports kids and families in 11 countries and territories in a growing global network. Hospitals, clinics, specialty camps and other eligible nonprofit facilities are able to publish their needs on Starlight.org so donors can simply point, click and support their facilities of choice. Projects in need of funding are as diverse as the communities they support. www.starlight.org

State of New Jersey Board of Public Utilities: Assistance with utility bills if having trouble affording it. Click “Assistance” on the left for more information: www.nj.gov/bpu/assistance


**Stomp the Monster:** provides financial and other support to cancer patients, their families, and caregivers. Families must fill out application and wait several weeks for response. Available online at: http://www.stompthemonster.org

**Stupidcancer:** The largest US-based charity that comprehensively addresses **young adult cancer** through advocacy, research, support, outreach, awareness, mobile health and social media. Whether you are a patient, caregiver or family member, newly diagnosed, living with metastatic disease or several years out from diagnosis, Stupid Cancer is here for you. We believe that you have the right to survive with dignity and quality and be treated age-appropriately every step of your journey. Being disease-free does not equate to "cure" and when the doctor says, "go home," that's not the end of the story. Join us. www.stupidcancer.org

**Sunrise Day Camp:** Sunrise Association Day Camps are the world’s only dedicated day camps for children with cancer and their siblings, provided completely **free of charge.** Main website: http://sunrisedaycamp.org. Local Staten Island website: http://sunrisedaycamp-statenisland.org

**Team Impact:** Serves kids across the northeast, covering New England, New York, New Jersey, and Pennsylvania, that are facing life threatening diseases by matching them with college athletic teams. www.goteamimpact.org.

**The Tears Foundation:** funding for funeral and burial expenses for infants up to one year. Also has a support group for bereaved parents that meets monthly at 1924 State Hwy 35, Suite 9C, Old Tudor Village. www.thetearsfoundation.org; or call: 253-200-0944.

**Teens Living with Cancer:** For and about teens with cancer with resources, message boards, information, etc. www.teenslivingwithcancer.org


**Ulman Cancer Fund for Young Adults, The:** Networking and support group, educational materials, scholarships for young Adults. www.ulmanfund.org

**United Healthcare Children’s Foundation:** Medical grants to help children gain access to health-related services not covered, or not fully covered, by their family’s commercial health insurance plan. http://www.uhccf.org/apply/learn-more-about-medical-grants/grant-application-criteria/

**Universal Service Fund:** The State of New Jersey created the Universal Service Fund (USF) program to help make energy bills more affordable for low income customers. The goal of the USF program is to help ensure that income eligible New Jersey utility customers pay no more than 6% of their annual income for their natural gas and electric service combined.

**Walk In Sunshine Charity:** Walk-in Sunshine is an organization whose premise is to be there for parents both financially and spiritually, who have lost young children. https://www.walkinsunshinecharity.org/

**YMCA Community:** Services and Assistance to our community. Youth Counselling, Youth Development, Healthy Living Responsibility. Contact person: Rhonda M. Anderson, President. Address: Patterson Ave, Shrewsbury, NJ, Phone: 732-671-5550 ext 121. Email: randerson@cymca.org
Zichron Shlome Refuah Fund: Provides a variety of assistance to Jewish families whose child has cancer. See website for details: 1319-51st Street Brooklyn NY 11219 www.zsrf.org/services.php

https://www.nj.gov/dcf/families/support/success/Just wanted to add that the programs at each location do seem to vary as far as what is available. Some link to resources for financial assistance while others have independent funding and link to resources. I had initially thought that they would all be the same but one of my families reported being approved for a large chunk of security deposit. I called them just for clarification and sure enough, they had independent funding. The centers also have a number of events for families.
**When calling individual hospitals, use main number and ask for the Social Worker Department**

**ALFRED I. DUPONT HOSPITAL FOR CHILDREN, Wilmington, Delaware**
Advanced inpatient and outpatient pediatric care in more than 30 specialties: see website for specific details,
intensive and acute pediatric care in a family-centered, kid-friendly environment, pediatric research that helps
advance breakthroughs and cures. Main number: 302-651-4200

**CHILDREN’S SPECIALIZED HOSPITAL**
**INPATIENT LONG TERM CARE, OUTPATIENT, EARLY INTERVENTION, PRESCHOOL:**
**VARIOUS LOCATIONS THROUGHOUT NEW JERSEY:**
Children’s Specialized Hospital is the nation’s leading provider of inpatient and outpatient care for children from
birth to 21 years of age facing special health challenges — from chronic illnesses and complex physical
disabilities like brain and spinal cord injuries, to developmental and behavioral issues like autism and mental health.
*Call main number for specific information as well as proper location:* Bayonne, Clifton, Egg Harbor Township, Fanwood, Hamilton, Mountainside, New Brunswick, Newark, Roselle Park, Toms River (two locations), Warren.
**MAIN PHONE: 1-888-CHILDREN, 1-888-244-5373**

**CHILDREN’S HOSPITAL OF PHILADELPHIA (CHOP), Philadelphia**
Considered one of the premier pediatric facilities in the country, specializing in cancer, cardiology and fetal surgery. CHOP ranks high in all 10 pediatric specialties, with dominant positions in diabetes and endocrinology, pulmonology and neonatology. Main Number: (215) 590-1000
**Specialty Care Centers** are located throughout New Jersey and Philadelphia.
Website: [www.chop.edu/location/speicalty-care](http://www.chop.edu/location/specialty-care) for a list of locations.
New Patient referrals or second opinions: 267-426-0762

**CHILDREN’S REGIONAL CENTER IN CAMDEN, COOPER UNIVERSITY HOSPITAL, CAMDEN, NJ**
Level III Neonatal Intensive Care Unit (NICU) treats full-term and premature infants with medical and surgical
problems related to premature birth, respiratory, metabolic or birth disorders, Renowned Pediatric Emergency
Department with fellowship-trained physicians, distinct waiting areas and rooms specifically designed to meet
the needs of infants and children. Main number for appt. 1800-8 Cooper or general info on specific dept.

**HACKENSACK UNIVERSITY MEDICAL CENTER**, Hackensack, NJ
**Joseph M. Sanzari Children’s Hospital**
Comprehensive program for children, adolescents and young adults (until age 22), that offers patients a multidisciplinary approach to treat all types of cancer and blood diseases. Our Blood and Marrow
Transplant Program is the only pediatric stem cell transplant program in the state of New Jersey. Research team gives our patients access to more than 100 cutting-edge clinical trials. Main: 551-996-2000

**JERSEY SHORE MEDICAL CENTER, Neptune, NJ**
**K.Hovnanian Children’s Hospital**
Main: 800-560-9990 or 732-775-5500

**MEMORIAL SLOAN-KETTERING MEDICAL CENTER, New York**
First Pediatric Day Hospital to minimize as much as possible the number of nights our patients spend in the hospital. Today, we provide about 90 percent of treatment for children and young adults with cancer in an outpatient setting, allowing most of our patients to leave the hospital with their families at the end of the day.
Main number: 212-639-2000. Appt. by phone: 800-525-2225

**MONMOUTH MEDICAL CENTER, Long Branch, NJ**
**The Unterberg Children's Hospital at Monmouth Medical Center, Valerie Fund Children's Center.**
Unique combination of medical care, counseling, and other services it provides. The Valerie Fund Children's Centers comprise the largest network of healthcare facilities for children with cancer and blood disorders in New Jersey and Philadelphia hospitals. See website for other hospital location.
Main number: 732-923-7250

**MORGAN STANLEY CHILDREN’S HOSPITAL** (formally Babies & Children’s’ Hospital (Columbia Presbyterian), New York
The Department of Pediatrics is committed to using inspired science and translational research that focuses on novel discovery that addresses the greatest threats facing children in the 21st century, including obesity and malnutrition, diabetes, heart disease, cancer, infectious diseases, asthma, prematurity, and adolescent health, and moves the discoveries. See website for specific information: Click on “Patient Care” for a list of areas, then click what applies.

**MORRISTOWN MEMORIAL HOSPITAL, Morristown, Summit, and Pompton Plains, NJ**
**Goryeb Children's Hospital**
**Overlook Hospital and Chilton Medical Center**
**Valerie Fund Children's Center**
Provide personalized, comprehensive medical care to children and adolescents with cancer and blood disorders.
**Morristown:** 973-971-6720, **Summit:** Overlook Hospital 908-522-2353, **Pompton Plains:** Chilton Medical Center 973-971-6720

**MT. SINAI KRAVIS CHILDREN’S HOSPITAL, New York**
Child & Family Support Programs offers a number of family-focused services, programs and activities specially tailored to assist you and your child before and during a hospital stay. For information or to arrange a tour: Phone: 212-241-6797

**NEWARK BETH ISRAEL MEDICAL CENTER, Newark, NJ**
Children’s Hospital of NJ
Valerie Fund Children's Center
Specialized services to treat ill and injured children from newborn to adolescent years as well as preventive programs that promote wellness in the community. Main Number: 800-843-2384 or 973-926-7000.

NEW YORK PRESBYTERIAN HOSPITAL,
Through our active research program, we have made extraordinary contributions to the understanding of childhood diseases and the development of measures for prevention and treatment. Works closely with Morgan Stanley Children’s Hospital of New York Presbyterian, 212-305-2500 and Phyllis & David Komansky Center for Children Health, 212-746-5454.

NYU MEDICAL CENTER, New York
A broad spectrum of pediatric specialties who perform rotations in emergency medicine, cardiology, critical care, hematology and oncology, neonatology and infectious diseases. See Website for all the different locations and specialties such as the Hassenfeld Children's Center for Cancer and Blood Disorders. Main number for Pediatric Specialist: 855-698-5437

ST. BARNABAS MEDICAL CENTER, Livingston, New Jersey
Valerie Fund Children's Center
Saint Barnabas Medical Center is a major teaching affiliate of Rutgers New Jersey Medical School, a major clinical campus for the New York College of Osteopathic Medicine, and affiliated with the St. George's University School of Medicine. Many different pediatric services such as the Valerie Fund Children Center are available. See site for all information under “Services”

ST. CHRISTOPHER'S HOSPITAL FOR CHILDREN, Philadelphia, PA
Offers many services for children including oncology. Some other areas are developmental disorder, orthopedic disability, heart condition, or debilitating allergy—or for a chest cold, earache, school physical or scheduled immunization. See site for a full list of services. Main number: 1-888-CHRIS KIDS (247-4754)

ST. JOSEPH’S REGIONAL MEDICAL CENTER, Paterson, NJ
St. Joseph’s Children’s Hospital
Provides advanced care for children from birth to 21-years-of-age. St. Joseph’s offers a full spectrum of specialty and subspecialty services including Neonatal and Pediatric Intensive Care Units, a dedicated Pediatric Emergency Room as well as the Regional Craniofacial Center, Center for Feeding and Swallowing Disorders, Concussion Center, Cystic Fibrosis Center. Children’s Hospital services are conveniently available in Clifton, Fair Lawn, Hoboken, Paramus, Paterson and Wayne. Main number: 973-754-2500

ST. PETER'S MEDICAL CENTER, New Brunswick, NJ
The Children’s Hospital at Saint Peters
Saint Peters offers a variety of services for children. See site for specific needs. Main number 732-745-8600.
Children’s Hospital main number: 732-565-kids (5437)
UMDNJ- ROBERT WOOD JOHNSON MEDICAL SCHOOL, New Brunswick, NJ
The Cancer Institute of New Jersey
Offers a variety of services for children. Main number: 732-235-6793
HOSPITAL-BASED PROGRAMS

Cancer Institute of New Jersey: Grant from NIH to develop a comprehensive cancer treatment center in NJ. 195 Little Albany Street, New Brunswick, NJ 08901, Main number: 800-4-Cancer or 800-422-6237.

St. Jude Children’s Research Hospital: No child is denied treatment based on race, religion or a family's ability to pay. is to advance cures, and means of prevention, for pediatric catastrophic diseases through research and treatment. 1-888-226-4343

Tomorrow's Children's Institute: Psychosocial support groups for patients and family members. Bilingual services. Hackensack Medical Center, 30 Prospect Avenue, Hackensack 07601; Main number 551-996-5500.

The Valerie Fund: For children with cancer and blood disorders. Financial assistance, medical and emotional support through a team approach. Central office: 2101 Millburn Avenue, Maplewood, NJ 07040; (973)761-0422 or 1-800-8VALERI.
  Newark Beth Israel Medical Center
  Cooper Hospital, Camden
  Monmouth Medical Center, Long Branch
  Overlook Hospital, Summit (Out-patient only)
  Morristown Memorial Hospital
WISH ORGANIZATIONS

**Cherished Creations:** Enrich and empower the lives of seriously-ill children and the underprivileged, giving them hope for a brighter tomorrow. Wishes granted for children up to age 21. 343 Snyder Avenue, Berkeley Heights, NJ 07922 Application and guidelines available on website: [www.cherishedcreations.com](http://www.cherishedcreations.com)

**Dream Come True:** Dreams begin with a referral and don’t end with the dream. Once a Dream Come True child always a Dream Come child. We stay with our children throughout their life. We offer dreams, various events where families get together for fun, support and fellowship. We also offer our children who are dream recipient’s college scholarships if they are able to attend college. If they unfortunately pass away, Dream Come True helps the family give the child the funeral they so richly deserve. Families in the Lehigh Valley area between the ages of 4–17. Phone: 610-865-3475. Website: [www.dreamcometrue.org](http://www.dreamcometrue.org)

**Kids Wish Network:** Started with the single purpose of granting wishes to children suffering with life-threatening conditions, but have since created additional programs to benefit kids worldwide, including Hero of the Month, Kids Wish Network On Tour, Holiday of Hope Gift Banks, A Child Forever Funeral Assistance. Phone: 727-937-3600 or 888-918-9004 [toll free]. [www.kidswishnetwork.org](http://www.kidswishnetwork.org)

**Make a Wish Foundation of NJ:** Grants wishes to any child with a life-threatening illness between the ages of 2½ and 18. One wish per child per lifetime. New Jersey Chapter Phone: 609-371-947/800-252-9474 or e-mail: jersey@wishnj.org, [http://nj.wish.org/](http://nj.wish.org/)

**Marty Lyons Foundation, The:** Fulfill the special wishes of children chronologically aged three (3) and seventeen (17) years old, who have been diagnosed as having a terminal or life threatening illness by providing and arranging special wish requests. Wishes for kids ages 3 -17. New Jersey Chapter: Phone number: 631-543-9474. Email: mlf_hq@martlyonsfoundation.org

**Sunshine Foundation:** Sole purpose is to answer the dreams of chronically ill, seriously ill, physically challenged and abused children ages three to eighteen, whose families cannot fulfill their requests due to financial strain that the child’s illness may cause. Minimum age 2, maximum 21. Wishes only granted to those children who have never received a wish from another organization. Phone number: 215-396-4770 or Email: info@sunshinefoundation.org.
CAMPS AND RECREATIONAL PROGRAMS

CAMP HAPPY TIMES – Tyler Hill, PA. Sponsored by the Valerie Fund One week free overnight camp for NJ children with cancer, ages 5 - 21. Transportation provided; accessible for physically disabled. Application online. www.thevaleriefund.org

TEEN CAMP HAPPY TIMES - Same as above, but for four days only, and for ages 16-21.

HAPPINESS IS CAMPING - Our mission is to provide children with cancer and their siblings a residential camp experience together with sophisticated medical care for campers both on and off treatment. These special children come to this unique camp free of charge, where they can put aside their illness and do what kids like to do... have fun! Located in Hardwick, NJ. One to Six-week free summer camp for children ages 7 - 18 with cancer who are on or off therapy. May attend for whatever period health allows. Phone: 908-362-6733. www.HappinessIscamping.org

THE HOLE IN THE WALL GANG CAMP - Ashford, CT. Free week long or weekend overnight camp for children, ages 7-15, with cancer and other serious blood diseases. Accessible for physically disabled. Transportation is not provided. There are five 11-day camp periods. Camp: (203) 429-3444. Administrative office: (203) 772-0522.

CAMP SIMCHA (Project from Chai Life) - Glen Spey, NY. Overnight kosher camp for children with cancer and other life threatening illnesses or Camp Simcha Special, for children with chronic illnesses. At these, the only kosher overnight camps for sick kids and teens, campers trade hospital rooms and doctors’ offices for summers of fun and friendship that builds confidence and courage to persevere through adversity. Ages 6-16. Nominal registration fee; transportation provided. Chai Lifeline: 212-699-6661 or 877-Chai-Life. Summer number: 854-856-1432 or 888-756-1432. info@campsimcha.org.

CAMP SUNSHINE - Free year-round retreat in Maine; currently the only full-time facility in the nation whose sole purpose is to provide respite for the whole family. Children diagnosed with cancer, hematologic conditions, renal disease, systemic lupus erythematosus, and who have undergone solid organ transplantation as well as bereaved families. Phone: 207-655-3800 www.campsunshine.org, sunshine@campsunshine.org.

KIDS CAMP.COM: Every kid deserves a summer at camp. Full directory of many camps; including special needs of any child. Email info that fits your family for information. www.kidscamp.com

CAMP JINKA – A free summer program in Monmouth County for children and teens whose lives have been impacted by the diagnosis of a brain tumor. http://campjinka.org/
AIR TRAVEL RESOURCES

Air Care Alliance
This is a nationwide league of humanitarian flying organizations whose volunteer pilots are dedicated to community service. Their website has an extensive central listing of free air transportation services that provide transport for patients, and sometimes family members, needing to get to a treatment center. For faster service, email mail@aircarealliance.org. Phone: 888.260.9707 or www.aircareall.org

American Miles for Kids
Program has provided worldwide support for children and their families, as well as for organizations dedicated to improving the quality of life for children with needs for medical, educational and social services issues.

The Something mAAgic Foundation®
Non-profit organization comprised of volunteers who are current and former American Airlines employees. We support the missions of Give Kids The World Village® and other children's organizations to create magical memories for children with chronic or life-threatening medical conditions. www.somethingmaagic.org

Angel Flight America – NE (Northeast)
Coordinates free air transportation for patients whose financial resources would not otherwise enable them to receive treatment or diagnosis, or who may live in rural areas without access to commercial airlines. Volunteer pilots and other aviation resources donate their time, airplane and operating expenses to ensure free non-emergency transportation for children and adults in need nationwide. Phone: (800) 549-9980; (978) 794-6868 http://www.angelflightne.org/

Continental
1-800-525-0280 Email: info@continentalairline.net or www.continentalairline.net

Corporate Angel Network, Inc.
Nationwide plane transportation for cancer patients to/from treatment centers. Phone: 914-328-1313 Patient Toll Free: 866-328-1313 email: info@corporateangelnetwork.org

http://www.corpangelnetwork.org/home

Delta
1-800-221-1212 Marketing Manager's office in Newark: 201-548-9400; will provide lowest rate available, waive any and all restrictions. Reservations should be made through the customer service department of their reservation office.

Miracle Flights for Kids:
To improve access to health care by providing financial assistance to low income children for commercial air travel to obtain special medical care. Flies children who are struggling with serious cancers and debilitating diseases to specialized medical treatment centers across the U.S. Any child needing medical treatment or seeking out a second opinion not available in their own home town may be eligible to receive air travel assistance through Miracle Flights, at no cost and as many times as needed. Phone: (702) 261-0494 or 1-800-FLY-1711. www.miracleflights.org, info@miracleflight.org, or flightcoordinator@miracleflights.org
Northwest
1-800- 221-1212
District Sales Office in New York: 212-557-4700
PHARMACEUTICAL RESOURCES

Cancer Supportive Survivorship, Drug Assistance Program
A comprehensive, online listing with links to many pharmaceutical companies.
http://www.cancersupportivecare.com/drug_assistance.html

The AstraZeneca Foundation Patient Assistance Program: Helps patients who do not have prescription insurance, who do not qualify for government-funded programs, and who do not have the means to pay for their AstraZeneca medications. To enroll in the program, physicians or patients should contact AstraZeneca by phone at 800-292-6363 or at their website, www.astrazeneca-us.com.

NeedyMeds: Not a patient assistance program, but rather a source of information on thousands of programs that may be able to offer assistance to people in need. NeedyMeds does not have an application, nor can we answer questions about individual assistance programs. We do offer a free drug discount card that may help you obtain a substantially lower price on your medications. info@needymed.com, www.needymeds.org

Partnership for Prescription Assistance: The Partnership for Prescription Assistance brings together America's pharmaceutical companies, doctors, other health care providers, patient advocacy organizations and community groups to help qualifying patients who lack prescription coverage get the medicines they need through the public or private program that's right for them. Many will get them free or nearly free. Select a medication or an active ingredient to see if there is any assistance available in paying for it. Access online at: www.pparx.org.

Pharmaceutical Manufacturer’s Patient Assistance Program: On line information and application with the pharmaceutical hotlines, where you will receive information about medication, assistance with insurance claim questions/appeals, and financial help for indigent families. Your child's physician may need to call specific hotlines on your behalf.

PHARMACEUTICAL HOTLINES

Amgen
Corp Headquarters: 805-447-1000
Amgen Foundation: www.Amgeninspires.com Patient Asst: See website for specific needs

Bristol Myers Oncology Division
To receive help paying for a product, go onto www.bms.com click “Product” or “Foundation”
Phone: 800-321-1335

Centocor Ortho Biotech
phone: 215-966-6000 email: info@sciencecenter.org

Glaxco Smith Klien
Burroughs Wellcome Company
Prescription information: 888-825-5249
Vaccines: 866-475-8222

Hoffman-La Roche (Rosch)
Phone: (908) 298-4000 www.roche.com

Schering Laboratories
PUBLIC/OTHER ASSISTANCE

Catastrophic Illness in Children Relief Fund: available to families of children age 21 or under when incurred medical expenses which are not otherwise covered exceed: 10% of income of $100,000, or 15% of income over $100,000. Income is measured for the calendar year in which the expenses were incurred and payment is made in following calendar year. Must live in NJ for at least 3 months.  www.state.nj.us/nj/about

Community Care Program for the Elderly and Disabled (CCPED)
The CCPED Medicaid waiver program provides services in an individual's home rather than in a nursing facility or institution. Eight services are available under CCPED: care management, home health services, homemaker, adult day health, non-emergency medical transportation, respite care, social day care and prescription drugs. All CCPED participants must enroll in Medicare Part D or have other prescription coverage. See Website for more specific information: https://www.caregiver.org/community-care-program-elderly-and-disabled-ccped

MODEL WAIVER I, II, III: These programs may provide a combination of both traditional medical services (i.e. dental services, skilled nursing services) as well as non-medical services (i.e. respite, case management, and environmental modifications) to those who meet both the established clinical and financial criteria. The purpose of the Waiver is to provide support services to an individual in the community to: Provide support to individuals who are reentering a community setting after a period of institutionalization. www.nj.gov/humanservices/dds/ohcs/waiver.

Home Care Expansion Program (HCEP)
Provides home care services to the elderly and disabled who are at risk of institutionalization and whose income and resources exceed Medicaid or CCPED standards. Service package is the same as CCPED. Income limits are $18,000 annually for an individual and $21,000 for a couple. Resources must be less than $15,000. Service costs are limited and clients may be required to share in their cost of care. The number of slots assigned per county varies. Applications can be made to PAAD by calling 1-800-792-9745.

New Jersey Family Care: Federal and state funded health insurance program created to help New Jersey's uninsured children and certain low-income parents and guardians have affordable health coverage. The entire application process can be completed by mail or online: www.njfamilycare.org or 1-800-701-0710.

Medically Needy: NEW JERSEY CARE…Special Medicaid Program. It provides medical coverage to certain needy individuals who may not be able to afford health care services, and who do not qualify for the regular Medicaid program.

New Jersey State Department of Health Special Child Health Services Program – County Case Management Units: Early intervention, educational issues, Medicaid assistance, medical equipment, and other services for children up to age 21. This resource is especially useful for helping clients with Medicaid and SSI procedures.

Pharmaceutical Assistance to the Aged and Disabled (PAAD): Provides prescription medicines and certain
pharmacy items requiring a $2 co-pay. Clients must be 65+ or receiving Social Security Disability benefits. No resource limit. Income Limit: Single: $13,650; Married: $16,750. Applications can be made to PAAD by calling 1-800-792-9745.

SSI (Social Security Supplemental Insurance Income): If your child has been diagnosed with cancer, you may be eligible to receive Supplemental Security Income (SSI) benefits on his or her behalf. The Social Security Administration (SSA) offers SSI benefits to disabled individuals who earn very little income. These benefits can be used to cover the cost of food, shelter, clothing, and medical bills. To learn more about SSI eligibility, continue reading. Applied for when the applicant has not paid into the system if financially qualified. Provides Medicaid (100% coverage). SSI central line: (800) 272-1111.

Financial Eligibility for SSI
Because SSI is a needs-based benefit program, applicants will need to meet certain financial requirements in order to qualify. Because children typically rely on parents for financial support, the SSA will evaluate a portion of the parent or guardians’ resources and income when determining a child’s eligibility. The act of allocating a parent’s income to the record of a child is called deeming. Learn more about deeming here: http://www.disability-benefits-help.org/blog/parental-deeming-process.

It is important to note, that once an applicant is approved for SSI benefits, they automatically become eligible to receive Medicaid coverage. Learn more about SSI here: http://www.socialsecurity.gov/ssi/text-child-ussi.htm.

Medical Eligibility for SSI
In addition to meeting the financial requirements outlined above, the SSA also requires that applicants meet certain medical criteria. First and foremost, the child’s condition must meet the SSA’s basic definition of childhood disability. If your child meets the SSA’s definition of disability, he or she will be evaluated based on criteria specific to his or her condition. These criteria are listed in the SSA’s official guidebook of qualifying disabilities—known as the Blue Book.

The requirements for childhood cancer can be found under section 113.00- Malignant Neoplastic Diseases. The conditions listed under this particular section include: malignant solid tumors, lymphoma, leukemia, cancer of the thyroid gland, retinoblastoma, brain tumors, and neuroblastoma. Be sure to look through each of these listings to identify the one that best matches your child’s condition. If your child does not meet any Blue Book listings, he or she may still qualify if you can prove that he or she has a type of cancer that causes significant, long-term limitations.

Application Preparation and Submission Read this section carefully. Once you have determined that your child meets all medical and financial requirements, you can begin the application process by contacting your local SSA office to schedule an interview appointment. Once you have scheduled your child’s interview, be sure to collect all relevant medical and financial records. These records will act as evidence of your child’s eligibility for SSI. Include a record of your child’s diagnosis, pathology reports, surgical notes, a history of hospitalizations, a history of treatments, and documentation of his or her reaction to treatments. It may also help to have a written statement from your child’s treating physician outlining your child’s condition and limitations. Being thoroughly prepared will likely speed up the application process and can potentially increase your child’s

What's Next?
The SSA will inform you whether or not your child’s application has been approved or denied. Typically, the decision making process can take several months. **However, many types of childhood cancer qualify for expedited processing through the Compassionate Allowance program. This program allows individuals with serious health conditions to be approved in as little as two weeks. To see if your child’s type of cancer qualifies, visit the SSA’s list of Compassionate Allowances:** http://www.ssa.gov/compassionateallowances/conditions.htm.

*If your child’s application is denied, do not panic. You are allowed to appeal the SSA’s decision within 60 days of receiving your notice of denial. Although it can be overwhelming to face the appeals process, it is often a necessary step toward receiving disability benefits. In fact, many more applicants are approved during the appeals process than are approved after the initial application.*

For information regarding disability benefits for teenagers or young adults older than 18, visit the following page: http://www.disability-benefits-help.org/disabling-conditions/cancer-and-social-security-disability.

PATIENT'S RIGHTS

NJ Department of the Public Advocate: Literature on special education needs and how to work with local school boards. Booklet "Special Rights for Special Children" free on request of parent. PO Box CN850, Trenton, NJ 08625-0850.

NJ Department of Insurance Consumer Complaints: enforces state insurance code and supervises the activities of private insurance companies. PO Box CN329, Trenton, NJ 08625-0329.

LAWS EFFECTING ECF FAMILIES

COBRA: (Comprehensive Omnibus Budget Reconciliation Act) provides for temporary 18 month extension of group health insurance at group rates in the event of a change in work circumstances.

**Family and Medical Leave Act** (http://www.dol.gov/whd/fmla/index.htm): The FMLA entitles eligible employees of covered employers to take unpaid, job-protected leave for specified family and medical reasons with continuation of group health insurance coverage under the same terms and conditions as if the employee had not taken leave. Eligible employees are entitled to:

- Twelve workweeks of leave in a 12-month period for:
  - the birth of a child and to care for the newborn child within one year of birth;
  - the placement with the employee of a child for adoption or foster care and to care for the newly placed child within one year of placement;
  - to care for the employee’s spouse, child, or parent who has a serious health condition;
  - a serious health condition that makes the employee unable to perform the essential functions of his or her job;
• any qualifying exigency arising out of the fact that the employee’s spouse, son, daughter, or parent is a covered military member on “covered active duty;” or

• Twenty-six workweeks of leave during a single 12-month period to care for a covered service member with a serious injury or illness who is the spouse, son, daughter, parent, or next of kin to the employee (military caregiver leave).

The New Jersey Division on Civil Rights enforces the New Jersey Family Leave Act (NJFLA), which requires covered employers to grant eligible employees time off from work in connection with the birth or adoption of a child or the serious illness of a parent, child or spouse. The NJFLA's definition of "parent" includes a parent-in-law or a stepparent. The NJFLA provides for up to twelve weeks of leave in a 24-month period. The 24-month period begins on the first day of the employee's first NJFLA leave.