

# Oncology Patient Resource Guide

Compiled by the Families of Fellow Patients

© 2013 Kelly Terry and Jodi Savare

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[Second Edition](#)

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For my Michael, with all my love. May you have a long and healthy life. I'm blessed to be your Mommy.

For you my beautiful "Cho Cho," you are my love, my inspiration, my hero, my daughter....N.E.G.U.

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Inputs are still welcome for future, yearly editions of this guide. Please send any to [pedoncoguideinputs@gmail.com](mailto:pedoncoguideinputs@gmail.com). Thank you for caring enough to share.

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## Introduction

If you are reading this, then you or a family member has probably been diagnosed with cancer. Know that you are not alone. Sadly, there are many families who have experienced what you are currently going through. It may be the most devastating news that you have ever heard. It may have come as a complete surprise, but know that there are **many** children that survive. They beat cancer and go on to live long, happy, healthy lives.

## Advice

This resource guide was compiled by the families of children currently being treated for cancer in New Jersey, New York, and the Philadelphia areas. We are sharing what we learned during our children's treatment so that your child's experience might be easier. Nothing in this guide should be assumed to replace the advice of your doctor.

### ***Finding a Doctor***

Following your child's diagnosis, you will need to make a huge decision: who will treat your child. This is not an advertisement for any particular doctor or hospital. Getting initial treatment with the hematologist/oncologist that diagnosed your child does not preclude you from switching at a later time. Many of the initial treatment protocols used are standard regardless of what doctor is administering them. Many pediatric oncologists are affiliated with the **Children's Oncology Group** (COG), the world's largest children's cancer research collaborative. To make your search easier there is an online directory of COG institutions by state (<http://www.curesearch.org/resources/cog.aspx>).

There are also many hospitals that provide *specialized* care based on your child's diagnosis. For example, if you are dealing with neuroblastoma, you may want to seek treatment at Memorial Sloan-Kettering Cancer Center (<http://www.mskcc.org/>) in New York or the Children's Hospital of Philadelphia (<http://www.chop.edu/>). Should you want a referral to the St. Jude Children's Research Hospital, you can reach them at the Referring Physicians Office, St. Jude Children's Research Hospital, 262 Danny Thomas Place, R3043/Mail Stop 285, Memphis, Tennessee 38105-2794, or 888-226-4343, 901-595-5295, 901-595-4011 (Fax). Do your research and find someone that you trust.

### ***Getting Emotional Support***

This is going to be an extremely difficult time for you and your family. You may be overwhelmed by profound sadness, fear, or feelings of guilt. Cancer will affect your entire family, even if they try to shield you from what they are feeling. Many facilities have social workers on staff. Avail yourself of their services for you, your child or someone else in your family, and allow yourselves time to settle into what will become your 'new normal,' knowing that nothing you did brought this upon your child.

The **Association of Pediatric Oncology Social Workers** (APOSW) is "a group of compassionate, professional oncology social workers. They are focused on enhancing the lives of children with cancer and blood disorders and taking care of the families of these children." According to their website, they

“advance pediatric psychosocial oncology care through clinical social work practice, research, advocacy, education, and program development.” To learn more about the services that they offer, please visit their site at <http://www.aposw.org/>.

People with cancer or their caregivers may also contact the **American Psychological Oncology Society** (APOS) ([www.apos-society.org](http://www.apos-society.org)) at their toll-free helpline (1-866-APOS-4-HELP, 1-866-276-7443) “to obtain a local referral for counseling and other support services” to manage cancer-related distress.

For parents of children treated at Valerie Fund Children’s Center locations, the **Mom2Mom** (<http://ubhc.udnj.edu/mom2mom/index.htm>) peer helpline (877-914-6662), offered through University Behavioral HealthCare (UBHC), is also accessible. They have moms, like you, trained in peer counseling and crisis support available to help as only someone who has been there can.

If you are up to it, introduce yourself to other parents in the waiting rooms and on the in-patient floor. You are not alone. There is a network of parents, just like you, without affiliation to any particular care center, that can listen and offer the lessons they learned. Some of us have created a private group on Facebook called **Momcologists Unite** (<https://www.facebook.com/groups/365508620143497/>). You are welcome to join us. Sharing experiences is what made this guide possible. It helps you learn what questions to ask and what tips and techniques worked for other parents, and sometimes more importantly, what did not.

## ***Accepting Help***

When people hear news of your child’s diagnosis they might ask what they can do for you. Even if your first impulse is to say that you are fine, be aware that you might be staying at the hospital for a while with your sick child—possibly a month or more. If you have other children, you might need someone to care for them, or drive them to and from school or after school activities, like soccer or dance class. You might appreciate prepared meals being delivered to your home or the hospital. Or, it might be nice to accept someone’s help cleaning your home, picking up medications, or bringing in fresh groceries. Think of all the things you normally do, and consider if you could use someone’s help taking care of any of them for a bit while you focus on getting your child better.

Online resources offered by sites, such as **CareCalendar** (<http://carecalendar.org/>) or **CaringBridge’s SupportPlanner** (<http://supportplanner.caringbridge.org/>), let you arrange needed support from the hospital or on the go. You list what things you need done, including directions as necessary; volunteers sign up to take care of the tasks; e-mails are sent to let you know who is doing what; and notifications are sent as gentle reminders. In the task detail sections, remember to include important information, including whom to reach in an emergency.

Consider letting others run a fundraiser for you. Although you might not need the financial support now, you never know what may come in the future. Your family may need it for medical bills or to do something incredibly fun at the spur of the moment.

Keep in mind that some cancer treatments take years to complete. Even if you don’t think that you need help now, down the road you might want assistance, or someone to just check in on you. It’s okay to ask someone to offer help to your family again, or at a later time.

If you are fine, and completely in control of everything that you need, suggest ways that people can help you and your family give back. Ask them to run blood drives; cook food for another family; or donate safe crafts, unused games, toys, or books to a local cancer center. Visit the [Giving Back](#) section of this guide for additional ideas.

## **Taking Back Control**

It is incredibly stressful to have a sick child and not be able to simply kiss away the pain. In this situation, you need to relinquish a lot of your control as a parent and put your faith and trust in oncologists and other medical professionals. However, there are things that you can do to assist in your child's treatment.

## **Educate Yourself & Ask Questions**

There are many available references that you can access to understand what is happening.

### **American Cancer Society**

**Website:** [www.cancer.org](http://www.cancer.org)

**Description:** “The American Cancer Society is in your corner around the clock to help you stay well and get well, to find cures, and to fight back,” as stated in [www.cancer.org](http://www.cancer.org). “[They] help you take steps to prevent cancer or find it at its earliest, most treatable stage. [They’re] in your corner around the clock to help you through every step of a cancer experience. [They] fund and conduct research that helps us better understand, prevent, and cure cancer. [They] work with lawmakers to pass laws to defeat cancer and rally communities worldwide to join the fight. [They’re] working every day to create a world with less cancer and more birthdays. Learn more about what [they’re] doing to ensure everyone has access to quality health care and how you can help.” They are available 24 hours a day at 800800-227-2345.

### **Children’s Oncology Group**

**Website:** <http://www.childrensoncologygroup.org/>

**Description:** Visit their page to learn more about childhood cancer and this organization. “The Children’s Oncology Group (COG), a National Cancer Institute supported clinical trials group, is the world’s largest organization devoted exclusively to childhood and adolescent cancer research. The COG unites more than 8,000 experts in childhood cancer at more than 200 leading children’s hospitals, universities, and cancer centers across North America, Australia, New Zealand, and Europe in the fight against childhood cancer.” In addition to maintaining clinical trials, the COG, together with CureSearch, also provides additional family handbooks and resources to cope with the battle ahead.

### **CureSearch / National Childhood Cancer Foundation**

**Website:** [www.curesearch.org](http://www.curesearch.org)

**Description:** According to their site, “CureSearch for Children’s Cancer is a national non-profit foundation that accelerates the cure for children’s cancer by driving innovation, eliminating research barriers and solving the field’s most challenging problems. [They] fight every day to make treatment possible and a cure probable for the 36 children diagnosed with cancer daily. [They] do this in three ways: [They] accelerate the cure for children at greatest risk of losing their battle with cancer by posing essential challenges to scientists and inviting teams to overcome them with novel research approaches. [They] support children’s enrollment in clinical trials that have the potential to save their lives today. [They] provide resources and education, so no child faces a cancer diagnosis without a fully equipped

support team behind them. Ultimately, CureSearch is working to change the odds for those children most at risk. ... [Their] mission is to fund and support targeted and innovative children's cancer research with measurable results, and be the authoritative source of information and resources for all those affected by children's cancer." As a leader in funding children's cancer research for the last 25 years, they recognize that although overall cure rates have increased from approximately 40% to 80%, the rates are unchanged for many of the more rare cancers, and only two drugs have been specifically developed for children's cancer. They are looking forward and trying to adapt. They are looking to advances in genomics and they "convened a Scientific Advisory Council featuring some of the brightest and most innovative thinkers in the cancer research field." ... Together, they "articulated the[ir] scientific vision to solv[e] the field's most intractable problems. CureSearch will continue to fund collaborative clinical trials so that children in treatment today have access to the latest medicines at hospitals close to home."

Additionally, to advocate for important childhood cancer issues before Congress, CureSearch hosts an annual Childhood Cancer Action Day in Washington, DC together with the other members of the [Alliance for Childhood Cancer](#). These events sometimes include advocacy training, and pre-arranged Capitol Hill visits with Congressional representatives and their staff.

### **National Cancer Institute**

**Website:** [www.cancer.gov](http://www.cancer.gov)

**Description:** The National Cancer Institute (NCI) is part of the National Institutes of Health (NIH), which in turn is one of the eleven agencies that comprise the Department of Health and Human Services (HHS). It is the Federal Government's principal agency for cancer research and training. NCI's mission, as reported by [www.cancer.gov](http://www.cancer.gov), is to "coordinate the National Cancer Program, which conducts and supports research, training, health information dissemination, and other programs with respect to the cause, diagnosis, prevention, and treatment of cancer, rehabilitation from cancer, and the continuing care of cancer patients and the families of cancer patients."

There are many **reference books** written on the subject of cancer. If you are looking for other guides written from the patient's point of view, or that of your family, you should consider [Childhood Leukemia: A guide for Families, Friends & Caregivers \(Patient Centered Guides\)](#) by Nancy Keene or [Living With Childhood Cancer : A Practical Guide to Help Families Cope](#) by Leigh A. Woznick. These books were written by mothers of children who fought and beat cancer. They will guide you through many of the topics covered here and more, as well as offering anecdotes from others who experienced what you might deal with going forward.

The oncologist may also give you a resource book. The National Childhood Cancer Foundation and Children's Oncology Group offer the [\*\*CureSearch Family Handbook\*\*](#) to help you learn about childhood cancer and how to care for your child. It is an excellent primer which describes important information, the types of childhood cancers, the tests and procedures, clinical trials, treatment and effects, and how to care for your child and family. Learning the terms used will help you participate more effectively in treatment.

Ask anything you are concerned about, and remember that no question is stupid. Writing questions down may help you remember to ask everything you want to cover. Sometimes you will be limited to doctors' rounds and you will want make the most of each visit.

## Different Types of Cancer

There are different types of cancer, and even within those, there are additional variants. Your child's specific diagnosis and risk factors will determine the course and length of treatment. Your doctor can explain the different types which include, but are not limited to:

- **Acute Lymphocytic Leukemia (ALL):** The Mayo Clinic's basic definition for ALL (<http://www.mayoclinic.com/health/acute-lymphocytic-leukemia/DS00558>) explains that it "is a type of cancer of the blood and bone marrow — the spongy tissue inside bones where blood cells are made." "'Acute' in acute lymphocytic leukemia comes from the fact that the disease progresses rapidly and affects immature blood cells, rather than mature ones. The 'lymphocytic' in acute lymphocytic leukemia refers to the white blood cells called lymphocytes, which ALL affects." Also known as Acute Lymphoblastic Leukemia, "it is most common type of cancer in children from 1 to 7 years old, and is the most common type of leukemia in children from infancy up to age 19," on the word of the Leukemia & Lymphoma Society (<http://www.lls.org/#/diseaseinformation/leukemia/acute-lymphoblastic-leukemia/>) . There are several subtypes, including:
  - Early pre-B ALL
  - Common ALL
  - Pre-B-cell ALL
  - Mature B-cell ALL (Burkitt leukemia)
  - Pre-T-cell ALL
  - Mature T-cell ALL
- **Acute Myeloid Leukemia (AML):** Wikipedia describes "Acute Myeloid Leukemia (AML), also known as Acute Myelogenous Leukemia, [as] a cancer of the myeloid line of blood cells, characterized by the rapid growth of abnormal white blood cells that accumulate in the bone marrow and interfere with the production of normal blood cells. AML is the most common acute leukemia affecting adults, and its incidence increases with age. Although AML is a relatively rare disease, accounting for approximately 1.2% of cancer deaths in the United States, its incidence is expected to increase as the population ages.

The symptoms of AML are caused by replacement of normal bone marrow with leukemic cells, which causes a drop in red blood cells, platelets, and normal white blood cells. These symptoms include fatigue, shortness of breath, easy bruising and bleeding, and increased risk of infection. Several risk factors and chromosomal abnormalities have been identified, but the specific cause is not clear. As an acute leukemia, AML progresses rapidly and is typically fatal within weeks or months if left untreated.

AML has several subtypes; treatment and prognosis varies among subtypes. Five-year survival varies from 15–70%, and relapse rate varies from 33-78%, depending on subtype. AML is treated initially with chemotherapy aimed at inducing a remission; patients may go on to receive additional chemotherapy or a hematopoietic stem cell transplant. Recent research into the genetics of AML has resulted in the availability of tests that can predict which drug or drugs may work best for a particular patient, as well as how long that patient is likely to survive." ([http://en.wikipedia.org/wiki/Acute\\_myeloid\\_leukemia](http://en.wikipedia.org/wiki/Acute_myeloid_leukemia))

- **Lymphoma:** On their website, the Leukemia & Lymphoma Society defines “Lymphoma [as] the name for a group of blood cancers that develop in the lymphatic system. The two main types are Hodgkin lymphoma and Non-Hodgkin lymphoma (NHL).”

“Hodgkin lymphoma has characteristics that distinguish it from other diseases classified as lymphoma, including the presence of Reed-Sternberg cells. These are large, cancerous cells found in Hodgkin lymphoma tissues, named for the scientists who first identified them. Hodgkin lymphoma is one of the most curable forms of cancer.”

“NHL represents a diverse group of diseases distinguished by the characteristics of the cancer cells associated with each disease type. Most people with NHL have a B-cell type of NHL (about 85 percent). The others have a T-cell type or an NK-cell type of lymphoma. Some patients with fast-growing NHL can be cured. For patients with slow-growing NHL, treatment may keep the disease in check for many years.” (<http://www.lls.org/#/diseaseinformation/lymphoma/>)

- **Neuroblastoma:** Research in Wikipedia shows that “neuroblastoma is the most common extra-cranial solid cancer in childhood and the most common cancer in infancy, with an annual incidence of about 650 new cases per year in the US. Close to 50 percent of neuroblastoma cases occur in children younger than two years old. It is a neuroendocrine tumor, arising from any neural crest element of the sympathetic nervous system or SNS. It most frequently originates in one of the adrenal glands, but can also develop in nerve tissues in the neck, chest, abdomen, or pelvis.”

“Neuroblastoma is one of the few human malignancies known to demonstrate spontaneous regression from an undifferentiated state to a completely benign cellular appearance. It is a disease exhibiting extreme heterogeneity, and is stratified into three risk categories: low, intermediate, and high risk. Low-risk disease is most common in infants and good outcomes are common with observation only or surgery, whereas high-risk disease is difficult to treat successfully even with the most intensive multi-modal therapies available.”

(<http://en.wikipedia.org/wiki/Neuroblastoma>)

- **Ewing Sarcoma:** Also stated in Wikipedia “Ewing sarcoma is a malignant round-cell tumor. It is a rare disease in which cancer cells are found in the bone or in soft tissue. The most common areas in which it occurs are the pelvis, the femur, the humerus, the ribs and clavicle.”

“Because a common genetic locus is responsible for a large percentage of Ewing sarcoma and primitive neuroectodermal tumors, these are sometimes grouped together in a category known as the Ewing family of tumors. The diseases are, however, considered to be different: peripheral primitive neuroectodermal tumors are generally not associated with bones, while Ewing sarcomas are most commonly related to bone.”

“Ewing sarcoma occurs most frequently in male teenagers, with a male/female ratio of 1.6:1. Although usually classified as a bone tumor, Ewing sarcoma can have characteristics of both mesodermal and ectodermal origin, making it difficult to classify.”

([http://en.wikipedia.org/wiki/Ewing\\_sarcoma](http://en.wikipedia.org/wiki/Ewing_sarcoma))

- **Wilms' Tumor:** Wilms' tumor, or nephroblastoma, is described as a “cancer of the kidneys that typically occurs in children, rarely in adults” in Wikipedia. “Its common name is an eponym,

referring to Dr. Max Wilms, the German surgeon (1867–1918) who first described this kind of tumor.”

“Approximately 500 cases are diagnosed in the U.S. annually. The majority (75%) occurs in otherwise normal children; a minority (25%) is associated with other developmental abnormalities. It is highly responsive to treatment, with about 90% of patients surviving at least five years.” ([http://en.wikipedia.org/wiki/Wilms\\_tumor](http://en.wikipedia.org/wiki/Wilms_tumor))

## Understand the Diagnosis Process & Procedures

If your child has Acute Lymphocytic Leukemia, over the course of the first month, your child will undergo a series of tests and procedures simultaneous with treatment. The results of these tests will give the doctors increasing insight into the type of cancer as well as your child’s risk level, which will ultimately affect the treatment process. Other tests, such as MRIs, echocardiograms, ultrasounds, and X-rays may also be needed from time to time to ensure your child’s well-being. If they haven’t already done so, you should ask your doctor to walk you through this process and what to expect.

**Blood tests** will be done before any treatment is given. Expect this every time your child sees a doctor—even for a flu shot. Your child may need a portacath, or **port** as it is typically called. Although it requires a surgery to have a port installed, you might consider it is useful to have. Without one, doctors or nurses will need to stick your child with an IV, or **PICC line**, to draw blood or provide chemotherapy. Much of the chemo is toxic to the skin, so having a port can be advantageous. A port also represents a risk of infection, so weigh the options after speaking to your child’s doctor.

In the beginning, **bone marrow aspirations** will be used at certain times to determine the cancer levels remaining in the marrow, or the chromosomal traits of the cancer. A small amount of bone marrow is removed through a needle inserted into the bone. These may be used again later if your child’s blood counts are low for extended periods or if he needs a stem cell transplant. Like bone marrow aspirations, **spinal taps** are performed under anesthesia. These tests are used to check the level of cancer in the spinal fluid. Throughout treatment, spinal taps are also used to deliver medications to the spinal cord and brain because the chemotherapy cannot penetrate the blood-brain barrier.

Once a diagnosis is made you may be asked to participate in cancer research studies, or clinical trials. Past studies have resulted in current treatment protocols. The oncologist can explain what participation means in terms of the treatment, and more information is available at the CureSearch site ([www.curesearch.org](http://www.curesearch.org)).

## Understand the Treatment Phases

For Acute Lymphocytic Leukemia, there are five distinct phases of treatment: **Induction, Standard Consolidation, Standard Interim Maintenance, Standard Delayed Intensification** and **Maintenance**. Some phases are more intense than others, and you should have your doctor walk you through the timelines, medications and expectations for each. Assume a mix of hospital visits, with lessening frequency over time, and medications to be provided by you at home. Visiting nurse services may be offered for certain procedures, and it never hurts to ask if you think that it can help. Overall, chemotherapy treatment for ALL lasts for roughly two and a half years for girls and three and a half years for boys.

Other types of cancer, or relapses, may also be treated with [radiation](#) and/or [bone marrow transplants](#). Treatment protocols will be different based on your child's diagnosis and risk level. It's important to discuss what your child will be given, why this is the best option, how long treatment will last, and what the side effects are.

At times you may need to step out of your comfort zone and do things that you never thought you'd need to, unless you are a nurse or doctor yourself. Remember that you are a crucial part of your child's treatment and that whatever you are asked to do is important, so try your best.

With every phase there are different concerns. Severely weakened immunity levels may require special precautions. For example, some doctors recommend using masks or bacteria-free diets in addition to good hand-washing, which should always be a part of your daily routine. Infection control is essential for most treatments as the chemotherapy will destroy immune systems. Hand washing can't be stressed enough. Get your friends and family into a routine so your child can stay healthy. Do not feel bad about stopping someone at the door of the hospital room, or your home, and asking them to wash their hands, put on a mask, or leave if they are showing symptoms of illness. People don't always realize how important that can be, but you should and need to be your child's best advocate.

Ask any questions that you have and follow medical advice as best as you can to protect your child. This also holds true for ending treatment. You can ask for a strategy session with your child's doctors when treatment finishes to learn what the next steps are and what to expect. You could ask if there are any side effects to stopping medications, withdrawal symptoms that you might observe, or future impacts resulting from treatment, along with any required follow up visits.

## Keep Notes & Copies of Blood Work

A lot of information will be given to you in a very short period of time, so it is easy to get overwhelmed. Certain information is essential to remember and monitor. The doctors and nurses will let you know what that is. Keeping notes may help you organize your thoughts and questions. Additionally, keeping records of your child's procedures and medication reactions can help you if you need to reference it for a doctor, a nurse, a specialist, or the insurance company—sometimes months later. Requesting and keeping copies of blood counts may be helpful in case you need to visit the emergency room (ER). The **Childhood Leukemia Foundation** provides **Hope Binders** (<http://www.clf4kids.org/index.php/what-we-do/hope-binder>) to help you manage all of this paperwork. Alex's Lemonade Stand also provides a secure **Online Treatment Journal** (<https://childhoodcancerjournal.com/>) for you to keep track virtually. The Online Treatment Journal is very detailed, going beyond the collection of general information to also capture diagnostic tests, transfusions, expenses, questions, daily blood counts, vital signs, nutrition, as well as great way to gauge symptoms and side effects over time. This is all married with a calendar for appointments, a journal, documents file, a virtual notepad and a contacts list. It takes the guesswork out of what you should be recording and is a great tool if you have internet access.

The doctors and nurses can explain how to interpret the blood count results. In simple terms, **white blood cells** called neutrophils fight infections. When you are immune-compromised, counts of neutrophils are low and you are susceptible to illness. You will often hear the term **Absolute Neutrophil Count (ANC)**, which is the percentage of white blood cells that fight infection. The lower the ANC gets, the higher your child's risk of infection becomes. This count will be used routinely to determine the risk of infection, whether your child gets chemo, and, at times, how much chemo he will get.

**Red blood cells** oxygenate the body. Low counts from chemotherapy may cause your child to be tired, or worse. **Platelets** allow blood to clot. Low platelet counts put your child at risk for bleeding. If your child's blood counts drop below certain levels, transfusions may be needed. Your doctor will tell you when this is necessary. Expect transfusions to take hours when they are required, and for your child to be medicated with Benadryl to avoid an allergic reaction.

## Learn When to Call the Doctor

You will be given **discharge instructions** before you leave the hospital explaining what medications to give your child and when it is necessary to call the doctor. It is important to understand them. In an emergency, call 911. You should call your doctor, even after hours, if your child has a fever greater than 100.4°F, especially if they are neutropenic (very low ANC).

You will probably be told to take your child to the hospital for treatment. If you are headed to the ER with a neutropenic child, ask if the doctor can call ahead and have a separate room ready. This can protect your child from exposure to additional germs. Even if your child isn't neutropenic, he may need blood work. You should ask if you should apply lidocaine cream/EMLA so there is no additional pain or delay once you arrive.

Antibiotics may be administered in the ER to treat bacterial infections, while viruses need to run their course. Fever reducers, like Tylenol, can help when your child has a virus, but ask your doctor before giving any to your child because it can mask a fever. Ibuprofen (Advil or Motrin) will most likely *not* be permitted because of the negative impacts on your child's platelets. Take care to warn all childcare providers of this.

Additionally, if you take your child to a healthcare facility or even a specialist unfamiliar with his case, you need to inform them of his condition and your doctor's orders regarding medications and procedures. Invasive procedures may do more harm than good because of the accompanying infection risk. Close communication with your oncologist is vital.

## Taking Medications

Each phase of chemotherapy will require a different mix of medications. When new medications start, ask for the side effect sheets so that you know what to anticipate. Keep in mind, some combinations of medications may also have unexpected reactions. If something changes with your child, you should take note of it and *tell the doctor*. For example, the combination of 6MP and methotrexate may cause hypoglycemia in some children. This reaction is not listed on the side effect sheets, but has occurred and can be managed with medical advice.

Realize that some medications come in different forms—pills, liquids, or even dissolving tablets. Some can be administered intravenously through a port or PICC line. This will only happen when you are at the hospital for an expected visit. Do not expect the ER to deliver chemotherapy. Additionally, the pills may change throughout the course of your child's treatment. If you ever want to double-check that the medication you were given is correct, you can visit a pill identifier site, such as the one offered by RxList <http://www.rxlist.com/pill-identification-tool/article.htm>, and enter the color, shape and any imprint.

Your pharmacy's phone number is one of the important pieces of information to have at the ready. Mail order medications are sometimes available from your insurance company. This is a good way to get a three months' supply for a single co-pay.

Liquids can often be flavored to improve the taste and reduce the bitterness. Asking the doctor and pharmacist what your options are (for medication forms and flavorings) before filling the prescription can prevent you from wasting money on meds your child will not take. There are some websites, such as the **Ped-Onc Resource Center** (<http://www.ped-onc.org/treatment/Pills/pills.html>), dedicated to helping you find ways to get your child take medications. Since this is more of a universal problem, there are many available options. You may need to try a few different things before you find the one that works.

Generic drugs may be provided by more than one manufacturer. If your child does well with a particular drug, you can request that manufacturer's product—even if it's a generic. Having the National Drug Code (NDC) will come in handy when making such a request.

You may be expected to give your child chemotherapy medications at home. If you are, you should ask for safe handling instructions to protect yourself and the other members of your household. For example, if your child can't swallow chemo pills, you need to take precautions before just crushing pills in your home. Pill cutters and crushers used for chemo can't be used for other meds, and gloves and masks may need to be worn for your safety.

Certain chemo can't be taken with food, and you need to follow the doctor and pharmacist's guidelines so that the chemo is as effective as possible. Consider the consequences of mixing chemo or other drugs into food even when it is allowed. It does not always taste good, it can be detected, and your child might not want to eat whatever you mix it into again. Feeding specialists may be available to give you advice on administering meds with the least amount of resistance. If your child regurgitates the first (or second, or third) dose, it may need to be repeated. The doctor or pharmacist can confirm when this is the case. Figuring out what works for your child might take time and more patience than you have. Just remember that your child needs this medication, take a break, and try again.

Some techniques that worked for our families are:

- Fruit roll-ups can be used to wrap pills to mask bad-tastes and simplify taking meds.
- Snow cone syrup, heavy syrup from canned peaches, or chocolate syrup can chase nasty-tasting pills or liquid medications.
- If your pharmacy doesn't offer flavored liquid medications, you may be able to flavor them yourself by mixing them with flavored syrups normally used for sodas or cocktails. Ask your pharmacist or doctor to be certain.
- A child may be trained to take oral meds through a needleless syringe by filling it with juice or soda in a similar flavor as the flavored liquid meds. Place the syringe in the back of the cheek and push a little bit at a time, letting him take breaks for a drink or cookie. When it is over, give him a reward. If he has siblings, have them also take the fake meds with the syringe and reward them too. "Playing doctor" in this way might help you with delivering the real med, **Dexamethasone**, a bitter tasting steroid.

- **OralFlo** (<http://www.oralflo.com/>) is a pill-swallowing cup. This works best for older children (usually over 4 years). When using this technique, you need to keep the cup and cover *completely* dry before putting in the pills. Otherwise, they will stick or start to break-down. Do not use this cup to take orally disintegrating tablets. Don't be discouraged if this doesn't work for your child. It doesn't work for everyone.
- Health food stores and online vendors sell **empty gelatin capsules**. You can insert the awful tasting pills inside before swallowing to cut down on the nasty flavors.
- **Nystatin** can be brushed all over the mouth to avoid thrush. Some of the hospital brushes can be really big for little mouths. Medical supply stores sell small oral swabs. If you let the child pick one, it might help.
- Mercaptopurine (or **6MP**) may be crushed between spoons in a plastic bag and then mixed into a tiny amount of mashed banana or poured between two stacked slivers of banana. Use a thin bed of sugar under the banana slivers so that you can get them off the plate. **Methotrexate** can be done the same way. You can use more banana for this med because there is no issue about taking it with food.
- **Zofran**, an anti-nausea med, is offered in dissolving tablets, which can be placed quickly into a child's mouth. It dissolves before the nasty taste sets in. Liquid forms of this med may be flavored if you prefer.
- If your child has a port, you will probably be asked to apply EMLA, or lidocaine, to the port location before coming to the hospital for routine visits, so that your child's port can be accessed without pain. Normally, EMLA is covered with Tegaderm which is *extremely* tacky and can be painful to rip off. **Glad Press and Seal®** is a great alternative for temporary needs. It sticks just enough to cover the EMLA and it doesn't hurt to remove it. If you need to use Tegaderm, ask for **AllKare** adhesive remover. It is an individually wrapped oily wipe that can make removing the Tegaderm much less painful.
- You can ask for **Medipore** and **HypaFix** as a dressing for Broviac sites instead of Tegaderm. It doesn't stick to skin. Patients might not even flinch when changing dressings with Medipore and HypaFix. The downside is that you need to change the dressing three times a week, but it won't hurt!
- **J-Tip** is an alternative to EMLA. It's a needleless syringe that administers lidocaine to injection sites. The benefit of J-Tip is that it takes only one minute for the area to get numb instead of the 30 minutes that EMLA traditionally takes.
- **ChloraPrep** is a topical solution that goes over the tape of incision sites. This is an added step to keep incision sites clean until they heal.

## **Easing Radiation Therapy**

Based on his diagnosis, radiation therapy may be needed to kill your child's cancer cells, or shrink a tumor or the dead tissue that remains after a tumor's removal. If your child requires radiation therapy, you may want to familiarize yourself with the basics in addition to speaking with your child's doctor. Nemours, a nonprofit organization devoted to children's health, provides an overview at their website: <http://kidshealth.org/parent/system/ill/radiation.html>. They describe the different types of radiation

used (X-rays, gamma rays, or proton beam therapy); what happens during both external and internal radiation therapy sessions; as well as, the possible side effects.

Radiation therapy requires precision. Your child needs to remain completely still and the machines used can be very intimidating. The technician might tattoo your child with dye and a needle, or mark your child's body with a permanent marker, so they can line him up with the machine every time. It is possible that your child will be strapped down to the table to make sure they stay in place. His modesty may be challenged because the radiation targets cannot be covered during the session and technicians will need to be present. You both should be prepared for this. If you are concerned that he will move or be too frightened or anxious, it is not unreasonable to ask for sedation.

The sessions vary in length from a few minutes to nearly thirty minutes, if not longer. Parents are not permitted to sit with their child during the sessions, so here are some suggestions to provide comfort while your child is in there alone. If the hospital has the capability, you may be able to watch and speak directly to your child throughout the treatment. However, if you can only watch the session on a monitor, it's recommended that you bring favorite CDs or a recording of your own voice for your child to listen to.

A mask or special bed may be necessary for the treatment, depending on where they need to apply the radiation. Although a bed that forms to your body might be cool to lie in, making a mask can be very upsetting. A plastic mesh mask is warmed and pulled tightly over his face to mold it to his features. It takes several minutes and may cause your child to feel claustrophobic. To lessen the traumatic aspects of the experience, you can ask for medication to relax him or request a technician who is experienced with kids. A great technician will make a world of difference with the comfort level for both child and parent. Another idea to make the mask less scary is to personalize it. Decorating it with butterflies or flowers, or making it look like a panda-face, helped our kids. It let the child have some say and made the experience of mask making and wearing a lot less threatening.

Therapy might go a bit easier if you plan something special to do after each session. Offering a new toy or doing something that your child enjoys may provide the necessary motivation to get him through the session. You can talk about it on the way there and enjoy it on the way home. Don't feel bad about it. Sometimes bribery is necessary. The radiation team might help you with this by offering a prize with every visit, or a **Bead of Courage** (<http://www.beadsofcourage.org/>) for each treatment.

Following the radiation therapy, the side effects aren't always immediate, but children have been known to exhibit skin reactions and/or nausea. Eliminating chemicals and fragrances from your soaps, lotions, and cleaning products might help with the skin issues, but since the radiation can cause a slight burn (almost like sunburn) and dry skin, you may be given a moisturizing cream for the affected area. Blood counts will probably drop and he may be more tired than usual, sometimes weeks later or for weeks on end. He may lose his hair or have dental problems associated with cranial radiation. Or, he might have more drastic reactions, and can require different treatments entirely to resolve them. Mention anything out of the ordinary to your doctor.

## ***Making Hospital Stays More Comfortable***

Now and then a hospital stay is necessary. Remember, when you need to go to the hospital, you may not have time to pack. Keep a packed bag for you and your child in your car or someplace you can grab

quickly on your way out the door to lessen the inevitable stress of this situation. Plan for a 72 hour hospital stay as a benchmark, and take your essentials. A [list](#) of things that other parents packed is attached in an appendix to help guide you. Nurses and hospital staff will try to make you comfortable by giving you a disposable toothbrush, toothpaste, sheets and towels in the hospital, but it's not a hotel. When you are there, they sometimes have facilities to wash your clothes yourselves. Ask if you need this service. Also ask them if they validate parking before you leave.

**ConKerr Cancer** (<http://www.conkerrcancer.org/>) provides cheery, colorful pillowcases to make hospital stays as pleasant as possible for chronically ill children and their parents. Sometimes the littlest thing can brighten your room and make your child smile. Along those lines, some hospitals offer a **free e-card service** for in-patients. By sharing the link to your [hospital's e-card site](#) with your child's building/room number, family and friends can send messages from home and words of encouragement to cheer on your little warrior.

Certain hospitals are teaching facilities. In these hospitals, expect visits and additional examinations from interns as well as your child's doctor. Keeping good notes may simplify answering their routine questions. They may be asking how your child is doing today, as well as how he presented with his illness, because part of their training is also learning how to take patient histories. Some in-patient floors allow you to opt out of rounds. Ask your nurse if you want to give your child, or yourself, a break.

There are usually books, movies, and playing cards available without even asking. In some hospitals the in-patient floor includes a playroom and **Child Life Specialists** to offer toys and a playmate. Music and art therapy may be offered there as well. Parents in need of a break for food or a walk can take it knowing that their child is safe and entertained.

Food selections are not always the best in the hospital. Nurses are typically able to offer take out suggestions. Guest menus may be available for caregivers who stay in the hospital with their child too, at a cost. Some rooms come equipped with refrigerators, and visitors can usually be coaxed into bringing food.

As a patient, you can call the kitchen/cafeteria manager and speak to him directly. Most people would never think to do this. But if the food isn't up to par, or there is nothing on the menu that you think your child will eat, call them. Explain your situation. We found the managers at the Monmouth Medical Center (MMC) and the Goryeb Children's Hospital at Morristown Medical Center to be very helpful. More than likely, they will send up anything that is available in the kitchen that you request. Also, if you are expecting more than an overnight stay, you can ask for bottled water to be delivered to your room.

If you are unable to stay in the hospital, you might look into facilities offered by **Ronald McDonald House** (<http://rmhc.org/>). There are many, included the ones below:

- Ronald McDonald House in Long Branch, 131 Bath Avenue, Long Branch, NJ 07740, 732-222-8755, Fax: 732 222-9363
- Ronald McDonald House in New Brunswick, 145 Somerset Street, New Brunswick, NJ 08901, 732-249-1222, Fax: 732 249-1439
- Ronald McDonald House in Philadelphia, 3925 Chestnut Street, Philadelphia, PA 19104, 215-387-8406, Fax: 215 386-4977

- Ronald McDonald House in New York City, 405 East 73rd Street, New York, NY 10021 212-639-0100, Fax: 212 472-0376

### Ronald McDonald Children's Charities

**Website:** [www.rmh.org](http://www.rmh.org)

**Description:** According to their website, "Ronald McDonald Children's Charities provide families stability and resources so they can keep their child healthy and happy. Whether those problems involve how to stay near and support a hospitalized child, how to afford staying together in another city while a child is undergoing treatment, or even getting basic medical and dental care in a vulnerable community. [They] not only help families address these problems, [they] provide solutions for these and other issues related to the health and well-being of children."

### ***Sharing News of the Diagnosis***

Amidst the whirlwind of activity surrounding an initial diagnosis and the flood of information, you may also find yourself inundated with messages and calls. Although they are concerned for you, telling family and friends the disappointing news over and over may compound your feelings of sadness.

You might want to appoint a spokesperson to relay the information and updates to everyone else. Or, you can consider setting up a **CaringBridge** site (<http://www.caringbridge.org/>) or a **CarePages** site (<http://www.carepages.com/>). **CaringBridge** is a free website that families dealing with serious health issues can use to share information. A personalized website for your child can be set up, by you or your spokesperson in minutes, with current information and pictures. It can be updated through journal entries from anywhere with internet access. The site is accessed with your child's name, or whatever you chose to call it. It is not searchable through search engines, and if you need more privacy, you can restrict access further with a registration process or a specific password. If you want to change the site later, all settings can be adjusted. Notifications of new postings are sent to anyone who registers for one; personal notes can be posted to the guestbook for you and your child to read; and you can organize help through the **CaringBridge SupportPlanner**.

### ***Taking Care of Yourself***

The last thing you probably would think to do right now is take time out to take care of yourself. But, you should try. We know, it's easier said than done, but, if you become sick, you will not be much use to your sick child or the rest of your family.

There may come a time when you read a list of the symptoms of stress and you realize that you have experienced some or all of them. Again, you are not alone in feeling this way. Eating right and exercise are ways to combat it on your own. Or, you can get additional support and help if you need it from the social workers, fellow cancer parents, or the American Psychological Oncology Society.

Considering that this can be an extremely tense time, you and your child may need a laugh to release some of that tension. You might want to read I Want to Grow Hair, I Want to Grow Up, I Want to Go to Boise (Children Surviving Cancer) by Erma Bombeck. Or, if you have access to the internet, consider visiting "The Never-Ending Squirrel Tale... You Know You're the Parent of a Kid with Cancer when"

website (<http://www.squirreletales.com/forfun/fun.html>). It's an irreverent look at our world from people who found something funny to share.

## ***Managing Insurance Issues***

One of the most stressful and time-consuming aspects of your child's illness can be dealing with the insurance company. Ways to minimize your stress include selecting an in-network doctor and an in-network hospital; this includes specialists that you will be directed to throughout your child's treatment. Calling and letting the insurance company know about the diagnosis may help, but the best advice is to keep good records and know what your coverage is—medical and pharmaceutical.

From time to time, you may need to act as a mediator between the insurance company and the hospital or another medical provider. More often than not, you will need to follow-up repeatedly on individual claims to protect yourself. Keep detailed records of these calls with dates, times and the name of the person you spoke with so you can reference them as needed later.

Some doctors will not be covered by your plan. Certain anesthesiologists fall into this category. If you are at an in-network hospital, being treated by an in-network doctor, and you didn't select the anesthesiologist or specialist, make sure that you mention that to your insurance representative when discussing your responsibility for any related bills. Be aware that there is an appeals process that you can use if necessary.

Some insurance companies offer case workers. If you avail yourself of these services, confirm what they can specifically do for you. Certain case workers assist with membership claims, while others are there to explain your medical condition. Some insurance companies also offer online assistance. Contacting them via the internet will allow you to reach them after hours, and will guarantee a written response.

Your office may have a Human Resource representative that is responsible for insurance issues, or a designated insurance representative that can intercede on an employee's behalf. Some children are so young when they are first diagnosed that this is the first time that they need prescriptions filled. Make sure that you have this representative's phone number just in case you need a quick intervention with the insurance company so your child can get needed medication.

## ***Getting Dental Care***

When your child starts chemotherapy, it impacts his entire body, and will also impact how you care for his teeth. If your child is young enough to still take multivitamins with fluoride, you may be told to stop them until the end of treatment. Although multivitamins may not be allowed, fluoride chewable tablets might still be an option to explore with your child's doctors and dentist.

Blood work and antibiotics may be necessary before each visit to the dentist, and you might need to get specific instructions from the oncologist as to what can and cannot be done. Some children have dental issues possibly worsened by their treatment, so do not ignore the care that a dentist can provide.

## ***Addressing School Considerations***

Parents of school-age children planning to enroll their child in classes should contact their doctor to determine if this is safe considering the stage of treatment and their child's health. Children with ANCs above 500 are usually fine to go to school, although they will still need to be careful when there. Young children may need to depend on their caregivers (teachers and school nurses) to ensure the child's continued well-being. Your child's doctor's office may be able to contact the school to advise how best to proceed. If your child is expected to be out of school for an extended period of time, consider applying for a **Hopecam** or a **Monkey In My Chair** discussed in our [Quality of Life section](#).

Contagious illnesses, like chickenpox, are especially concerning to immune-suppressed children, particularly since some are airborne. Your child's doctor may be able to conduct a varicella titer blood test to see how susceptible your child is to contracting the chickenpox illness prior to his re-entry to school. While in attendance, if someone else at school is contagious, expect to have your child home until the outbreak passes.

## **School Re-entry Program**

If your child is being cared for at one of the seven Valerie Fund Children's Centers located throughout NY, NJ and PA, you should take advantage of their School Re-entry Program

(<http://www.thevaleriefund.org/programs/reentry.php>). Paraphrased from their site, '[a]fter becoming sick, children may find it difficult to catch up with schoolwork, socialize with others, and/or function as a student while undergoing treatment. And, they aren't the only ones who are affected by their illness. Often schoolmates do not know how to relate to a sick child. The **Valerie Fund's School Re-Entry program** helps children successfully return to school after diagnosis or treatment. A child life therapist facilitates a school re-entry session in the child's classroom, based on the child's age group. At times, the therapist role-plays using dolls to help children better understand their classmate's illness. Their goal is to create a compassionate environment and enable a smooth transition during the child's return to school. After the presentation, the child life specialist leaves age-appropriate materials with the child's teacher for future needs, and is available for follow-up contact by phone or e-mail. As needed, the specialist can revisit the school if parents and/or teachers feel that doing so will make the patient more comfortable at school.'

## **Section 504 Plans & Individualized Education Programs**

In addition to your child's health, when planning to re-enter school, you should consider if their illness or treatment impacts their ability to learn. Social workers at the hospital may notify your state's Department of Health to plan for special needs services based on your child's health status. It might helpful have your child assessed by your state's **Early Intervention Services** or a local **Child Study Team**. Physical or occupational therapy in addition to other services may be offered. Schools are required to make accommodations for children with "medical or other disabilities" so that they all have "equal access to education." (<http://www.state.nj.us/education/students/safety/behavior/504/>). You may not think of your child this way, but you need to do your research and use terms that will get an appropriate, helpful response from the school.

According to LDOnline (<http://www.ldonline.org/article/6086>), "Section 504 [of the Rehabilitation Act of 1973], a civil rights law, prohibits discrimination on the basis of disabling conditions by programs and activities receiving or benefiting from federal financial assistance." Basically, a **504 plan** is an

accommodation plan for students who have a disability that “substantially limits a major life activity,” with learning being one of those activities. It requires that the school system provide accommodations that will allow the student to *access their learning* in the same way as their nondisabled peers. So, for instance, if a school has no wheelchair ramp and a child requires a wheelchair, accommodations have to be made for that student (e.g., a ramp has to be added). Another example, a student who has major allergies may require that an air conditioner be installed in their classroom so that they can function in the room during allergy season. For a student who has a chronic illness, a 504 plan may allow for a modified schedule (i.e., attending school for only  $\frac{1}{2}$  days or allow for a second set of books at home).

Schools vary in how they develop and implement 504 plans, but generally speaking there is a 504 committee that includes teachers, administrators, and relevant staff. They, along with the parents, will develop the plan that spells out what the disability is and what accommodations the school will provide. Schools will generally require medical documentation of the disability, but the actual law states that a student is entitled to a 504 when ‘a disability is suspected or when the student is treated as if a disability exists even if no medical diagnosis is available.’

**Individualized Education Programs (IEPs)** are used for children requiring special education through the protection of the Individuals with Disabilities Education Act (IDEA). An IEP is an individualized plan for a student who has a disability that impacts his *ability to learn*, and who requires some form of *supportive instruction* to be successful. Children with speech or language impairments, traumatic brain injury, or visual or hearing impairments fall under this category. Schools can be asked to provide speech and language therapy, occupational therapy, physical therapy, counseling services, psychological services, social services, and/or transportation. If, as a result of treatment, your child requires any of these services, avail yourself of them.

In summary, 504 plans offer accommodations or an alternate way or means for the child to access his learning whereas an IEP offers accommodations as well as modifications, to how and what the child learns. In an IEP, the actual content can be modified (i.e., a student with a learning disability may be required to learn fewer and more simple vocabulary terms, his homework may be reduced, or his grading may be modified.) Explore LDOnline or contact your school system for more information.

## Scholarships

### **Surviving and Moving Forward: The SAMFund for Young Adult Survivors of Cancer**

**Website:** <http://www.thesamfund.org/>

**Description:** The SAMFund is a non-profit organization focused on providing financial assistance to young adult cancer survivors. Its creator, Samantha Eisenstein Watson, is a transplant survivor herself. So, she understands how financially devastating cancer can be, in addition to physically devastating. She established this fund to help with post-treatment life. They “help supplement money that was lost during treatment” “so that these young adults can not only survive, but truly move forward.”

Grant and scholarship applications are accepted annually to assist with educational or professional goals, medical expenses, living expenses, insurance premiums, family-building costs, and much more. Applicants must be U.S. residents between the ages of 17 and 35 who are finished with active

treatment. Visit the web site for more information about eligibility guidelines, application submission, and other ways they assist young adults.

### **The Valerie Fund Scholarship Program**

**Website:** <http://www.thevaleriefund.org/programs/scholarships.php>

**Description:** Scholarships are offered in addition to the other medical and social services provided by The Valerie Fund. Children treated at any one of their seven facilities may apply for financial support to pay tuition for a post-secondary institution, including trade schools, two-year community colleges, and four-year colleges and universities. “The Valerie Fund is proud of the more than \$50,000 in scholarship money it’s given to 100 worthy students” since 2007. If you are interested in this program, please contact someone on staff at The Valerie Fund Center where you are, or were, treated.

### ***Giving Back***

While this probably won’t be feasible in the beginning, once your family settles into the ‘new normal’, you may want to find ways to give back to those who helped you or to repay the kindnesses from which you have benefitted. You might want to make a donation in your child’s name to an organization that has helped you, host an event or toy drive for the hospital, host a pediatric cancer research event, or even sponsor a child’s wish.

Remember that people who care about your family also appreciate feeling like they are helping you or your cause. You can suggest that they do any of the above or host or contribute to a fundraising event to help your family directly.

Getting children involved is another great way to give back while teaching your children the importance of charity. Help them with a lemonade stand or baking cookies to raise money for cancer research or with a brownie troop drive to collect wish list donations for a local Ronald McDonald house. They will feel good for doing a great deed, and they might even get a badge for it!

Donating blood or platelets is another wonderful way to donate life and save a child with cancer. Contact the blood bank at your local hospital if you are interested. Participating in the National Marrow Donor Program’s ([www.marrow.org](http://www.marrow.org)) **Be The Match Registry®** “offers you the unique opportunity to help a patient in need by donating bone marrow or umbilical cord blood.”

## **Childhood Cancer Resources**

A variety of resources are available to families coping with a diagnosis of childhood cancer or a blood disorder. Some offer emotional support, some offer financial assistance, some offer help around the house, and some offer gifts and wishes. Others offer advocacy for cancer research. We have listed them here so that you can find them easily to get the type of assistance that you need to make your life a little easier and happier.

## ***Advocacy***

Cancer research, education and public policy require advocates to make advances possible. These organizations make cancer advocacy their business.

### **Alliance for Childhood Cancer**

**Website:** <http://www.allianceforchildhoodcancer.org/>

**Contact Information:** [alliance@asco.org](mailto:alliance@asco.org), 571-483-1670 or 2318 Mill Road, Alexandria, VA 22314

**Description:** Following the American Cancer Society's National Summit Meetings on Childhood Cancer in 1999 and 2000, the Alliance for Childhood Cancer emerged. This united group "represents more than twenty national patient advocacy groups and professional medical and scientific organizations. ..."

Patient advocates, many of whom are either cancer survivors themselves or are parents of children with cancer, are joined by oncology professionals and others representing the multidisciplinary spectrum of cancer care in a unique alliance that brings concerned parties together to advance the interests of children with cancer." Their mission is "to provide a forum of national patient advocacy groups and medical and scientific organizations which meets regularly, shares ideas and concerns, and works collaboratively to advance research and policies to prevent cancer, and improve public education, and the diagnosis, treatment, supportive care and survivorship of children and adolescents with cancer."

Together their members host annual Childhood Cancer Action Days in our nation's capital.

### **Children's Cause for Cancer Advocacy**

**Website:** <http://www.childrenscause.org/>

**Contact Information:** <http://www.childrenscause.org/contact>, 202-336-8374/8375 or Children's Cause for Cancer Advocacy (CCCA), 750 First Street, NE, 7th Floor, Washington, DC 20002

**Description:** This is the leading national advocacy group focused on "less toxic and more effective pediatric cancer therapies" to increase survival rates while decreasing survivors' late effects from treatment. They are working "to expand resources for research and specialized care; and to address the unique needs and challenges of childhood cancer survivors and their families." According to their site, "CCCA leads efforts to ensure that these needs and perspectives of children with cancer are integrated into the highest deliberations on health care and cancer policy at the Federal level."

### **People Against Childhood Cancer (PAC2)**

**Website:** <http://curechildhoodcancer.ning.com>

**Contact Info:** [info@peopleagainstchildhoodcancer.org](mailto:info@peopleagainstchildhoodcancer.org)

**Description:** Visit PAC2 online to understand more about this advocacy community called People Against Childhood Cancer. Their mission is "to raise awareness of childhood cancer. They strive to take ACTION as 'One Voice United Against Childhood Cancer'!" They are trying to leverage a large community of voices to be heard. They want to "achieve a critical mass where [their] advocacy voice will be heard by the media, corporations and organizations that can help PAC2 raise awareness and direct funding to research to cure childhood cancer." "[They] are doing this for the kids. [They] will work together on Initiatives that are developed and implemented collaboratively".

## ***Airfare***

Travelling to treatment facilities sometimes takes more financially than you can handle. There are some resources that can assist. Social workers at your treatment center should be able to help you with these services.

### **Corporate Angel Network**

**Website:** <http://www.corpangelnetwork.org/index.htm>

**Description:** Per the Corporate Angel Network's site, they are "the only charitable organization in the United States whose sole mission is to help cancer patients access the best possible treatment for their specific type of cancer by arranging free travel to treatment across the country using empty seats on corporate jets. This not only improves the patients' chances of survival but at the same time, it reduces their emotional stress, physical discomfort and financial burden." Contact their Toll-Free Patient Line at (866) 328-1313 to see if they can assist your family.

### **Frequent Flyer Programs**

Major airlines used to have programs whereby a childhood cancer patient and a parent would be able to fly for free. Now, they typically require that you register for their Frequent Flyer mile programs and ask your family and friends to donate miles to you. Investigate which airlines fly between your home and the treatment center, and check before transferring miles because some airlines will charge a fee for this service.

## ***Bone Marrow Transplants***

### **Be The Match Foundation®**

**Website:** [www.marrow.org](http://www.marrow.org)

**Contact Information:** [http://marrow.org/Contact/Contact\\_Be\\_The\\_Match\\_Foundation.aspx](http://marrow.org/Contact/Contact_Be_The_Match_Foundation.aspx); 888-999-6743 for patients or families; or, 800-MARROW2 (800800-627-7692)

**Description:** As stated above, participating in the National Marrow Donor Program's ([www.marrow.org](http://www.marrow.org))

**Be The Match Registry®** "offers you the unique opportunity to help a patient in need by donating bone marrow or umbilical cord blood." The Be The Match Foundation® raises funds to help patients in need of a bone marrow or umbilical cord blood transplant receive the treatment they need. Specifically, a gift to Be The Match® Foundation provides financial assistance for patients who need help with treatment costs, funds medical research to keep advancing transplant science, and adds more donors to Be The Match Registry®, increasing the chances that more patients will find their match.

## **Blood and Marrow Transplant Information Network**

**Website:** <http://www.bmtinfonet.org/>

**Address:** 2310 Skokie Valley Road, Suite 104, Highland Park, IL 60035

**Contact Information:** 888-597-7674, [help@bmtinfonet.org](mailto:help@bmtinfonet.org)

**Description:** Visit their site to learn how the "Blood & Marrow Transplant Information Network (BMT InfoNet) is dedicated to providing transplant patients, survivors and their loved ones with emotional support and high quality, easy-to-understand information about bone marrow, peripheral blood stem cell and cord blood transplants. Whether you are just beginning the transplant journey or learning to manage the joys and challenges of survivorship, BMT InfoNet is here to help. [Their] goal is to empower you with credible information and emotional support, so that you can take a more active role in decisions affecting your health and treatment options before, during and after transplant."

## **Camps**

Free overnight camping experiences for children with cancer and their family members are offered by the following organizations. Applications are available online at the sites below. They need to be filled out by you *and* your child's doctor, so keep that in mind when looking at the submission deadlines.

### **Camp Adventure**

**Website:** [http://community.acsevents.org/site/PageServer?pagename=C\\_EA\\_CA\\_home](http://community.acsevents.org/site/PageServer?pagename=C_EA_CA_home)

**Location:** 75 Davids Dr., Hauppauge, NY 11788. Camp Adventure takes place on 27 acres of private seashore at Camp Quinipet at Shelter Island, located between the north and south forks of Eastern Long Island, New York.

**Available Dates:** Visit the website or call for available dates.

**Phone:** 800800-ACS-2345

**Description:** As said at their site, "Camp Adventure is a free, fun-filled, one week, sleep-away camp program for children with cancer and their sisters and brothers, ages 6-18," offered by The American Cancer Society. It is a place where kids can just be kids while receiving the medical attention they need from a caring and qualified staff 24 hours a day. "Camp Adventure offers traditional activities such as sports, arts and crafts, swimming, music, and nature activities." Other activities include team challenges, scavenger hunts, archery, and talk time. Offered evening and special events are full of surprise and wonder, and gives kids a break from the reality of cancer treatments.

### **Children's Oncology Camps of America**

**Website:** <http://www.cocai.org/>

**Description:** This organization's mission is "to strengthen the international community of camps for children with cancer and their families through networking, advocacy, and education." The camps located in the New Jersey area are already included in this list. Many camps for children with cancer also offer 'sibling sessions'. Inquire about those offered in your area and encourage your local 'cancer camps' to offer these sessions. Check out <http://www.cocai.org/> to find camps with sibling programs in your area.

### **Camp Happy Times**

**Website:** <http://www.thevaleriefund.org/programs/camp.php>

**Location:** Tyler Hill Camp, Route 371, Tyler Hill, PA 18469

**Available Dates:** Visit the website or call for available dates.

**Description:** Available to Valerie Fund patients (former and present), Camp Happy Times (CHT) is "a free one-week overnight camp experience for children aged 5-21 who have or have had cancer. ... CHT promotes friendship, independence, and a spirit of cooperation for cancer patients and survivors. The CHT philosophy is to provide a recreationally therapeutic environment that engages participants while building self-esteem, confidence, trust and friendship."

Their site confirms that "medical personnel are on premises 24 hours a day," and that the "infirmary staff is comprised of Valerie Fund doctors and nurses, who administer chemotherapy, evaluate blood counts and prescribe and administer medications to the campers throughout the week. ... Valerie Fund social workers and child life specialists are also on site and available at all times."

## Camp No Worries

**Website:** [www.campnoworries.org](http://www.campnoworries.org)

**Location:** YMCA of Burlington County, 59 Centerton Road, Mt. Laurel, NJ 08054

**Available Dates:** Visit the website or call for available dates.

**Description:** Visit their site and you will see that “Camp No Worries is a summer camp created solely to give NJ residents [Ages 6-16] with cancer and their siblings an opportunity to relax, enjoy themselves and forget about their troubles for one week every summer. It’s a place that allows children facing a diagnosis of cancer to just be kids. It’s a place of happiness, friendship and new adventures. It’s a place of camaraderie and acceptance where everyone knows first-hand what it’s like to live with cancer. And, it’s a true summer camp experience in every sense of the word.” Still, pediatric oncologists are on-call 24 hours a day for any necessary medical needs.

## Camp Quality New Jersey

**Website:** <http://www.campqualityusa.org/nj/Home.aspx>

**Location:** Varies by season, including Camp Happiness on a beautiful lake in NW Jersey.

**Available Dates:** Visit the website or call for available dates.

**Description:** As said at their site, “Camp Quality is a volunteer driven, volunteer run and community funded non-profit, 501 (C) (3) organization that provides free camping experiences and year-round support programs for children with cancer, and their families. Camp Quality New Jersey’s programs are focused to care for the emotional needs of children with cancer [(ages 5-17)] and their families. As they face the ‘challenging days’ and celebrate the good ones, a support network of peers provides tremendous strength and hope.”

“Camp is held for one-week during the summer, with additional support programs continuing throughout the year such as reunions and family outings [and camp experiences].” Camp Quality will help parents experience the fun that their kids have during the summer while families get to know each other better, and an improved support system is created.

## Camp Sunshine

**Website:** <http://www.campsunshine.org/>

**Location:** Sebago Lake, Casco, Maine

**Available Dates:** Visit the website or call for available dates.

**Phone:** 207-655-3800

**Description:** “Nestled alongside the shores of beautiful Sebago Lake, Camp Sunshine provides [a week long] respite, support, joy and hope to children with life-threatening illnesses and their immediate families through various stages of a child’s illness. ... The camp has the distinction of being the only program in the nation whose mission is to address the impact of a life threatening illness on every member of the immediate family—the ill child, the parents, and the siblings. ...The year-round program is free of charge to all families, and includes meals, 24-hour on-site medical and psychosocial support. Bereavement groups are also offered for families who have lost a child to an illness.” Check out their site to learn more.

## **Double H Ranch**

**Website:** [www.doublehranch.org](http://www.doublehranch.org)

**Location:** 97 Hidden Valley Road, Lake Luzerne, NY 12846

**Available Dates:** Visit the website or call for available dates.

**Phone:** 518-696-5676

**Description:** The Double H Ranch, co-founded by Charles R. Wood and Paul Newman, provides “specialized programs [free of charge] and year-round support for children and their families dealing with life-threatening illnesses.” As stated on their site, their purpose is “to enrich their lives and provide camp experiences that are memorable, exciting, fun, empowering, physically safe and medically sound.”

## **Happiness is Camping**

**Website:** <http://www.happinessiscamping.org/>

**Location:** 62 Sunset Lake Road Hardwick, NJ 07825

**Available Dates:** Visit the website or call for available dates.

**Phone:** Office: 718-295-3100 or Camp: 908-362-6733

**Description:** Happiness Is Camping was founded in 1980. It's “a regular sleep-away camp for normal kids; girls and boys who just happen to have cancer.” They serve about 400 children, girls and boys aged 6-15 years with cancer (or their siblings). “The camp is free to all, supported by donations and volunteer staff members. The medical staff from Memorial Sloan-Kettering Cancer Center, Montefiore and other fine facilities, provide 24 hour medical supervision of the highest quality, with facilities for kids requiring chemotherapy, children at risk of bleeding and infection or with significant physical disabilities.

...Happiness Is Camping is a special place where the remarkable is routine. “

## **Haven of Hope for Kids**

**Website:** <http://www.havenofhopeforkids.org/>

**Location:** Hope, NJ

**Available Dates:** Visit the website or call for available dates.

**Phone:** 908-459-4340

**Description:** This organization provides a no-cost retreat for families caring for a child with a life-threatening illness right here in New Jersey. It's a place to take a break from your life and spend quality time as a family: swimming, fishing, hiking, horseback riding, bowling, ice skating, sledding, skiing or visiting local farms or parks. There are ways to enjoy this place year-round. If you are interested, check out their site to verify that your child is treated at one of the referring hospitals and contact a social worker there.

## **Hole in the Wall Gang Camp**

**Website:** <http://www.holeinthewallgang.org>

**Location:** 565 Ashford Center Road, Ashford, CT 06278

**Available Dates:** Visit the website or call for available dates.

**Phone:** 860-429-3444

**Description:** Founded in 1988 by Paul Newman, The Hole in the Wall Gang Camp is a non-profit, year-round center serving children and their families coping with “cancer, sickle cell anemia, and other serious and life-threatening conditions.” Through summer sessions and family weekend programs at the

Camp in Ashford, Connecticut, as well as year-round outreach to hospitals and clinics throughout the Northeast, the Camp helped over 17K children in 2011 alone. “Activities include archery, mini golf, swimming, boating, fishing, horseback riding, arts and crafts, sports, theater and camping; all are designed to include every child and ensure that no child will fail.” All services are free of charge. If you are interested, visit their site for more details and an application.

## **Lighthouse Family Retreat**

**Website:** <http://www.lighthousefamilyretreat.org/>

**Location:** Retreats are held along the Florida panhandle between Destin and Panama City Beach in an area known as 30A.

**Available Dates:** Visit the website or call for available dates.

**Phone:** 678-290-2955

**Description:** The Lighthouse Family Retreat offers a free five day beach vacation for the families of cancer patients to bring back some normalcy. Their site mentions some highlights of a Lighthouse Family Retreat experience. These “include families spending time together, moms and dads getting away for a special date night, kids having a blast at the ice cream party and movie night, incredible beach and pool games that everyone participates in, a tie dye day, a dance party under the stars and a talent show that tops all talent shows.” If you are interested, visit their site for more details and an application.

## **Ronald McDonald Camp**

**Website:** <http://www.philarmh.org/our-programs/ronald-mcdonald-camp/>

**Location:** The camp is located at Camp Timber Tops in Greeley, Pennsylvania in the Pocono Mountains, just a three hour drive from Philadelphia.

**Available Dates:** Visit the website or call for available dates.

**Description:** Ronald McDonald Camp is a free week-long overnight camp for Juniors (Ages 7-12) and Seniors (Ages 13-17) who are currently undergoing treatment, or who have been treated for cancer. One sibling per camper is also allowed to attend for a \$100 donation.

Camp experiences are personalized to age groups. According to their site, “programs include all elements of a traditional camp including swimming, hiking, and sports.” “Campers can also participate in a variety of creative, therapeutic, and fun activities including art & crafts, yoga, and more. ... It's a week of fun and friendship, and freedom from being different. It's a chance to experience new activities and acquire new skills in a supportive, nurturing environment. It's a time when kids can talk openly about cancer and everybody else understands.”

Their “camper-to-counselor ratio is 2-1”, and they “are able to provide one-on-one assistance when necessary.” Their “wellness center is staffed 24 hours a day by a medical and psycho/social staff of pediatric oncologists, nurses, and social workers from The Children's Hospital of Philadelphia.”

## **Cancer Resource Registries**

There are so many resources available to you, that we could not possibly list all of them here. These are resources that we use, or think may be helpful to you. Some are registries of additional resources that we also found valuable.

### **Association of Cancer Resources Online (ACOR)**

**Website:** <http://www.acor.org/>

**Description:** According to this registry's website, "ACOR is a unique collection of online communities designed to provide timely and accurate information in a supportive environment. It is a free online lifeline that offers access to over 150 mailing lists that provide support, information and community to everyone affected by cancer and related disorders."

### **Ped-Onc Resource Center**

**Website:** <http://www.ped-onc.org/index.html>

**Description:** The Ped-Onc Resource Center "is a web site for parents, friends, and families of children who have or had childhood cancer. This resource center was created by and for people who know young people who are recovering from cancer. Most of the contributors to this site are members of the ACOR pediatric cancer mailing lists, especially ped-onc, ped-onc-survivors, and ALL-kids." At this site you will find additional information about family support, information on cancers, treatment issues, survivorship issues, grief, and ways to get involved. They also have more links to other helpful sites and journal searches, and lists of resources. This site's links are current as of 2011 and includes a very detailed index so you can find what you are looking for quickly.

## ***Financial Support***

If you are in need of financial assistance because of your child's illness, there are a number of foundations and funds that might be able to help you. We have listed some of them here to save you the research time.

If your child is being treated at a Valerie Fund Children's Center, you should contact the Valerie Fund social workers. They might be able to help you by filling out and submitting financial aid forms. Additionally, they might be able to provide you with donated gift cards for gas or groceries, if you are in need.

You should consider also requesting assistance from the hospital foundation associated with the facility providing your child's treatment. These philanthropic arms of the hospital exist to help you pay all the bills that the hospital sends. You can ask the social workers or contact the foundation directly.

## **Foundations & Funds**

### **A Mother's Kiss**

**Website:** <http://www.amotherskiss.org/>

**Address:** P.O. Box 513, Ridge, NY 11961

**Phone:** 631-924-2770

**Description:** "A Mother's Kiss is a 501(c) 3 not-for-profit organization formed for the purpose of providing emotional and financial support to the families of childhood cancer patients in the Long Island and Metro-New York area." For assistance please contact the child's pediatric social worker, or contact the foundation directly.

### **AshleyCan Pediatric Cancer Foundation**

**Website:** <http://www.ashleycan.org/>

**Contact Info:** info@ashleycan.org or AshleyCan Foundation, P.O. Box 6, Bourbonnais, IL 60914

**Description:** Visit this site to learn more about how this foundation “is dedicated to raising awareness for pediatric cancer, providing assistance to families of children with cancer and providing funding for research.”

### **The Beauty Foundation**

**Website:** <http://www.beautyfoundationnj.com/>

**Address:** 68 White Street, Suite 113, Red Bank, NJ 07701

**Phone:** 732-719-9909

**Description:** According to their site, “The Beauty Foundation’s mission is to alleviate the tremendous physical, emotional and financial strains that cancer treatment places on families. [They] help remove the burdens that families face when one of their members is fighting cancer. [They] raise money to offset the expenses they incur which aren’t covered under insurance, including child care, household expenses, transportation costs associated with treatment and other needs from lifestyle changes caused by cancer. The Beauty Foundation is a 501 C3 non-profit organization that supports and empowers families who are actively fighting cancer through direct monetary grants. The Beauty Foundation also supports the development of educational materials and provides support to local cancer centers. [Their] goal is to help inspire courage, strength and confidence that [are] needed to fight cancer.”

### **The B+ Foundation**

**Website:** <http://www.bepositive.org/>

**Phone:** 302-654-6207 or 302-563-8389

**Contact:** joe@bepositive.org or B+ Foundation, 101 Rockland Circle, Wilmington, DE 19803

**Description:** The Andrew McDonough B+ Foundation honors the memory of this 14-year-old athlete who sadly earned his wings after a short, but inspiring battle with AML. They “do good” by providing financial and emotional support to families dealing with childhood cancer as well as funding childhood cancer research grants. They hope to spread Andrew’s message to “be positive” despite the challenges you face.

### **CancerCare**

**Website:** [http://www.cancercare.org/get\\_help/assistance/index.php](http://www.cancercare.org/get_help/assistance/index.php)

**Phone:** 800800-813-HOPE

**Description:** “CancerCare is a national non-profit, 501(c)(3) organization that provides free, professional support services to anyone affected by cancer: people with cancer, caregivers, children, loved ones, and the bereaved.” CancerCare programs—including counseling and support groups, education, financial assistance and practical help—are provided by professional oncology social workers and are completely free of charge. CancerCare has online support group bulletin boards that are monitored and mediated by CancerCare professionals.

CancerCare may give you \$175 a year for general expenses. They'll send you an application, your doctor will have to fill out part, and you just fax it into them. This support is based on need, so you need to stress limited assets.

### **Catastrophic Illness in Children Relief Fund**

**Website:** <http://www.state.nj.us/humanservices/cicrf/home/>

**Phone:** 800-335-FUND

**Who is Eligible:** In order to qualify for this NJ State assistance:

- “The child must have been 21 years or younger when the medical expenses were incurred.”
- “The family must have lived in New Jersey for three months immediately prior to the date of application. Migrant workers may be eligible, temporary residents are not.”
- “In any prior, consecutive, 12 month period, dating back to 1988, eligible expenses must exceed 10% of the family's income, plus 15% of any excess income over \$100,000.”

**Description:** As reported on this site, “the Catastrophic Illness in Children Relief Fund is a financial assistance program for New Jersey Families whose children have an illness or condition otherwise uncovered by insurance, State or Federal programs, or other source, such as fundraising. The Fund is intended to assist in preserving a family's ability to cope with the responsibilities which accompany a child's significant health problems” by defraying some medical costs. Please note that your family can apply for this every year that it is needed.

### **Children's Cancer Fund of America, Inc.**

**Website:** <http://www.ccfoa.org/home.html>

**Address:** Children's Cancer Fund of America, Inc., 2317 West Emory Road, Powell, TN 37849

**Phone:** 1-888-418-6062

**Description:** On their website, The Children's Cancer Fund of America, Inc. explains that it “operate[s] exclusively as a charitable organization dedicated to assistance and support of children suffering with cancer, and their families, through financial aid.” “CCFOA programs fight the ravages of childhood cancer in the following ways: Financial assistance - via [its] ‘Checks for Children Program’; Education - Providing health related information regarding prevention, detection, and treatment of childhood cancers; Public information - Advising the public as to the existence and purposes of Children's Cancer Fund of America; [and] Referral - Providing a Resource List of other organizations who may have additional help for the child with cancer, and their family.”

'If your child is between the ages of 0 – 19, call 1-888-418-6062 to ask for an Application for Assistance. They will send an enrollment packet with instructions and the necessary forms, including a diagnosis verification to be signed by a medical professional. Once CCFA receives the completed application and signed diagnosis verification the first check will be sent (possibly \$50 per month). Applications must be renewed every 6 months for continued assistance.'

### **Emmanuel Cancer Foundation**

**Website:** [www.emmanuelcancer.org/](http://www.emmanuelcancer.org/)

**Phone:** 908-322-4323

**Description:** “Founded in 1983, the Emmanuel Cancer Foundation serves New Jersey's children with cancer and their families by providing emotional, material and emergency financial support. ECF kids and their families receive a comprehensive package of: emotional support, counseling, and advocacy services through ECF's team of professional Caseworkers; material assistance, made available through the four Regional Centers; Regional Directors coordinate the collection and distribution of food, toys, new clothes, and household items to families. In addition, Regional Directors serve as a major fundraising arm for the foundation; [providing] emergency financial assistance for families in a crisis situation.” Read more at their site and contact them for support.

### **Family Reach Foundation**

**Website:** <http://www.familyreach.org/>

**Phone:** 973-394-1411

**Description:** According to their site, the mission of the Family Reach Foundation “is to provide financial relief and heartfelt support to families fighting cancer. ... The majority of [their] funds are dedicated to families with a child or a young adult who is being treated for a pediatric or other type of cancer.” ... “The common element is that children are involved and impacted, either directly as patients, or indirectly within the family.” They raise funds through a variety of events and fundraising programs to help eligible families pay for significant expenses that amass during the patient’s treatment. These include: “everyday home bills that accumulate due to lost wages of parents (e.g., mortgage, utilities, insurance premiums, etc.); transportation to care centers and lodging for family; child care; palliative care; or other needs.” If you are in need of their assistance, check out their site to see if your child is being treated at one of the hospitals in their network and contact your hospital’s social worker.

### **Fighting Children’s Cancer Foundation**

**Website:** <http://www.fccf.info/>

**Phone:** 908-429-2121

**Description:** As stated at <http://www.fccf.info/>, “the goal of the Fighting Children’s Cancer Foundation (FCCF) is to provide emotional and financial assistance to children afflicted with cancer and to their families. [They] are committed to supporting the families in their efforts to improve the quality of the ill child’s life. Another objective of the FCCF is to heighten awareness of the plight of these children and their families to generate additional support for the Foundation’s efforts.” Anyone requiring assistance will need to fill out a Case File Application that has to be validated by the treating Pediatric Hematologists/Oncologists and Licensed Social Worker assigned to the child.

### **Foundation for Children with Cancer**

**Website:** <http://www.childrenwithcancer.org/>

**Contact Info:** 414-550-5847 or 11414 W. Park Place, Suite 202, Milwaukee, WI 53224

**Description:** Visiting their site, you can see that the mission of this 501c (3) non-profit foundation “is to financially assist the families of children with cancer. By providing tangible and direct financial support, such as mortgage payments, insurance premiums and utility bills, families are given a greater opportunity to focus on their child’s treatment and recovery.” If you are in need of assistance, please read their guidelines for financial assistance (<http://www.childrenwithcancer.org/awareness-programs/financial-assistance-program/>) and contact them if you think they can help. Note that you need to be referred by your child’s doctor or social worker. Assistance may take up to three weeks to process.

### **Gifts of Hope Foundation, Inc.**

**Website:** <http://giftsofhopefoundation.org/>

**Phone:** 800-768-5916

**Description:** In keeping with their mission stated online, the Gifts of Hope Foundation “provide[s] financial support and resources to families who are affected by their child’s chronic illness diagnosis; and creat[es] collaboration between families, medical providers, insurance companies and caring individuals, [to] provide support to families and their children.” Apply for financial assistance at their site.

### **Joe Andruzzi Foundation**

**Website:** <http://joeandruzzifoundation.org/>

**Description:** As stated on their site, "The Joe Andruzzi Foundation is tackling cancer's impact by providing financial assistance for patients and their families, as well as funding pediatric brain cancer research." "Monetary awards are made to assist individuals and families with their daily living expenses. Candidates are required to provide verification of cancer diagnosis as well as documentation to support their need for financial assistance. This program typically provides assistance for the following daily living expenses including: electrical, telephone, car, gas/heat, water, rent/mortgage, and other similar expenses. [Note that] all financial assistance monies are paid directly to the providers of such services."

### **The Leukemia & Lymphoma Society**

**Website:** <http://www.lls.org/diseaseinformation/getinformationsupport/financialmatters/patientfinancialaid/>

**Description:** The Leukemia & Lymphoma Society may give you \$150 just for having a blood cancer. You can get this aid every year, which begins each July. The application is online. Keep in mind that funds tend to run out, so apply early.

### **Managed RX Plans**

**Website:** <http://managedrxplans.com/>

**Description:** Managed RX Plans is a pharmacy that helps by paying for medication. For people who have insurance plans that qualify, they will pay for all co-pays, shipping and they will automatically send refills every month. If you set up home delivery for all meds through the insurance company, you simply need to ask your doctor to call in your scripts to this Managed RX pharmacy, and you won't have to pay for anything. Be aware that this service has a catch: your *employer* may be charged for the medication.

### **The Patient Advocate Foundation**

**Website:** <http://www.patientadvocate.org/>

**Phone:** 800-532-5274

**Description:** This is a national non-profit organization that serves as an active liaison between the patient and their insurer, employer and/or creditors to resolve insurance, job retention and/or debt crisis matters relative to their diagnosis through case managers, doctors and attorneys. You can request a case worker to solve your issues, such as getting free medication, funding for caregiver expenses or locating a cancer-experienced personal trainer for rehabilitation.

### **Rema Hort Mann Foundation**

**Website:** <http://www.rhmfoundation.org/>

**Description:** The Rema Hort Mann Foundation conducts a grant program for cancer patients to assist individuals undergoing treatment in the greater New York Metropolitan region, by strengthening their personal support networks. To qualify, you need to be treated at a participating hospital and nominated by someone from there. Grants range from \$500 - \$2,500 and support mostly travel funds, accommodations, telephone calls and other related expenses.

### **Thomas Peterpaul Foundation**

**Website:** <http://www.thomaspeterpaul.com/>

**Description:** According to their site, "the Peterpaul family has created The Thomas Peterpaul Foundation (TPF) in Thomas' honor. It is a non-profit 501(c) 3 organization devoted to raising funds for pediatric cancer research and to improve the quality of life for patients & their families. TPF grants

funds directly to families in need whose child is battling cancer.” The TPF identifies a patient family with the assistance of both hospital social workers and child life specialists, so if you are in need, contact these professionals.

## Government Programs

### NJ Family Care

**Website:** <http://www.njfamilycare.org/>

**Phone:** 800-701-0710

**Description:** “NJ FamilyCare is a federal and state funded, [low to no cost] health insurance program created to help New Jersey's uninsured children [(18 and under)] and certain low-income parents/guardians to have affordable health coverage.” They explain online that “it is not a welfare program. NJ FamilyCare is for families who do not have available or affordable employer insurance, and cannot afford to pay the high cost of private health insurance”. If you believe you may qualify, check out their site for additional eligibility requirements and an application.

### NJ Medicaid

**Website:** <http://www.nj.gov/humanservices/dmahs/clients/medicaid/>

**Description:** According to their site, “Medicaid provides health insurance to parents/caretakers and dependent children, pregnant women, and people who are aged, blind or disabled. These programs pay for hospital services, doctor visits, prescriptions, nursing home care and other healthcare needs, depending on what program a person is eligible for.” Medicaid might pay for some, or all, of your medical bills, which sometimes include transportation and prescription costs. In some states, Medicaid covers children under the age of 21 if they are hospitalized for 30+ days, regardless of parental income.

“To be eligible for New Jersey Medicaid, a person must: be a resident of New Jersey; be a U.S. Citizen or qualified alien; and meet specific standards for financial income and resources. For questions about New Jersey’s Medicaid program, call 800-356-1561, or your County Welfare Agency (<http://www.nj.gov/humanservices/dfd/programs/foodstamps/cwa/>)”.

If your income disqualifies you, you should ask about a **Katie Beckett Waiver** (<http://www.patientadvocate.org/index.php?p=534>). The Patient Advocate Foundation explains that “also known as the Deeming Waiver, or the 2176 Model Waiver, the Katie Beckett Waiver is a federal waiver that is intended for children from birth to eighteen years of age with a chronic disability. It entitles children to Medicaid that would not otherwise qualify due to their parent’s financial status.” You can read more about ‘Deeming’ and when a ‘Child Can get Medicaid’ at <http://www.socialsecurity.gov/ssi/text-child-usi.htm>.

### Social Security Benefits

**Website:** <http://www.socialsecurity.gov/>

**Phone:** 800-772-1213

**Description:** The **Supplemental Security Income (SSI)** program (<http://www.socialsecurity.gov/pgm/ssi.htm>) “pays benefits to disabled adults and children who have limited income and resources.” To apply for aid, visit the website, click on the SSI tab at the top, then click on ‘apply for a child.’ “To apply for a child you will need to complete an Application for SSI and a Child Disability Report. The report collects information about the child’s disabling condition and how it

affects his/her ability to function. At this time, only the Child Disability Report can be completed online" (Click on Step 3 Child Disability Report, and Start Report). Please contact them to schedule an appointment to complete the SSI application. They will help you in person or by phone. For more information, access <http://www.ssa.gov/pubs/10026.html>.

## Personal Fundraising Organizations & Ideas

### Conducting Personal Fundraising

Many times, financial burden comes along with the other challenges cancer brings. Hosting fundraising events, walk-a-thons, 5K races, yard sales, t-shirt or bake sales, even lemonade stands can help defray some of your medical or associated expenses.

There are special considerations to note when fundraising for yourself, or when others are fundraising for you especially if your child is applying for Supplemental Security Income (SSI) or Medicaid eligibility. In this case, you need to keep the collected funds in a **special needs trust**, and the trust must pay your child's medical providers, etc. directly. If your family receives the money directly, or if your child's Social Security Number (SSN) is used to open a bank account, your child might lose the SSI or Medicaid benefits, or have the benefit reduced. ([http://www.ssa.gov/OP\\_Home/ssact/title16b/1613.htm](http://www.ssa.gov/OP_Home/ssact/title16b/1613.htm)) Read more about this in the 2009 article entitled "Maintaining Eligibility for SSI and Medicaid: What can a Family Member or Special Needs Trust purchase for a Person with Disabilities, and what is a Person who is receiving SSI or Medicaid allowed to own?" by John S. Kitchen, JD, LLM, *One Sky Services Library*. ([http://www.oneskyservices.org/files/library/sp\\_needs\\_trust\\_kitchen.pdf](http://www.oneskyservices.org/files/library/sp_needs_trust_kitchen.pdf))

### Considering Non-profit Organizations

One way to receive tax-deductible charitable contributions from others is to create a 501(c)(3) non-profit organization. Your state's Office of the Secretary of State can provide you with the [information](#) and forms necessary to start a non-profit charitable organization and you can contact the IRS to apply for 501(c)(3) non-profit status. These non-profit organizations are exempt from income and (sometimes) property tax. There are many online resources that might help you create one on your own, including wikiHow (<http://www.wikihow.com/Start-a-501c3-Non-profit-Organization>). If you are contemplating this, also seriously consider consulting an attorney experienced in non-profit law to avoid preventable issues.

When consulting with your attorney, you should discuss the options, including working with an existing national, regional or local non-profit that has a similar mission or focus, or requesting a fiscal sponsorship. With so many established charities, it is possible that a registered charity is already working to achieve the same charitable intentions that you have in mind. By volunteering your talent, skills, financial resources, or just a great idea, together you may achieve your goal faster, or improve on your initial idea. Additionally, by joining forces, you can leverage their charitable registration; proven infrastructure (without duplicating start-up costs); knowledge of legal obligations; operations team, management/administrative staff and services; donor, business, and media relationships; as well as their goodwill.

You do not need to limit your search to those organizations within your community, or those with your exact intended mission. A charity with different programs, or one operating in a different locale, may be the ideal organization to partner with, as they may be looking to increase their range of services or area

served. When approaching charities to discuss the possibility of working together, have a well-thought-out plan to accomplish your programming goals that is in line with their core mission and objectives in order to be taken seriously. This includes a resourcing strategy.

Even if they do not want to merge, they may be interested in offering a **fiscal sponsorship** for your project. You can benefit from their tax-exempt status while remaining somewhat flexible based on your sponsorship agreement.

If you still want to start from scratch, keep in mind the extremely competitive landscape for new non-profits. Reflect on everything that it will take to go it alone and consider applying for grants to fund and sustain your efforts.

### ***Incorporating a Non-Profit***

To incorporate your non-profit organization within the state you are operating, start by writing the articles of incorporation, by-laws, mission statement, and conflict of interest policy; and, naming officers, etc. You file through your state's Department of Treasury and will receive a Certificate of Incorporation in return. Then, you can process the federal filing. Currently, state incorporation varies, but will cost you around \$100; and federal filing costs \$750. Attorney fees for state incorporation vary by law firm, and if you are lucky, you can find one to do it pro-bono. Otherwise, it can cost thousands. You may want to consider using an online legal document preparation service such as **LegalZoom** as appropriate.

Once you file for your 501(c)(3), it takes about six months to receive your tax-exempt status from the IRS. Provided your application is approved, donations are tax-deductible retroactively from the filing date with the federal government. At that point, your non-profit is exempt from paying income tax to the federal government; but, you have to file separately within your state to become exempt from paying state sales tax on items purchased for your organizations. Once you are exempt from paying sales tax, submit ST-5 (Certificate of Exemption from Sales and Use Tax) Forms to your vendors. Note that you still need to pay sales tax in any state in which you are not incorporated, or licensed to do business; and, you also need to pay tax on travel expenses and FCC surcharges on phone calls.

You will be required to file a 990 Form with the federal government each year, as well as an annual report within your state, and with the state's Department of Consumer Affairs. You can file the EZ Form for the 990 until your sustained annual revenue surpasses \$250,000, then you will need to file the long form. Some states also require certified audits of your annual financial statements. The threshold for this requirement varies by state. In NJ, for example, you are not required to file certified financial statements until your annual revenue reaches \$500,000. Expect these to cost roughly \$10,000 in accounting fees for the audit alone.

### ***Using Existing Fundraising Sources***

There are some existing online sources that you can try to use to raise money. The following are examples, and the sites may no longer be operational, but it will give you an idea of what resources might be out there.

#### ***American Giving Awards (Example, May No Longer be Operational)***

**Website:** <http://www.nbc.com/americanGivingAwards/index.shtml>

**Description:** "Through the American Giving Awards program, Chase will grant \$2,000,000 to charities, recognizing five (5) previous Chase Community Giving grant recipients, chosen by our Facebook fans as

well as some Chase.com users. One (1) organization will receive a \$1,000,000 grant, followed by four (4) grants in the following amounts: \$500,000, \$250,000, and two grants of \$125,000. Each organization will represent one of five (5) pre-determined categories recognizing the ‘building blocks’ of our communities!”

### **Cancer Fears ME<sup>TM</sup>**

**Website:** <http://www.coolkidscampaign.org/cancer-fears-me/>

**Phone:** 410-560-1770

**Description:** “Cancer Fears ME<sup>TM</sup> is trademarked by the Cool Kids Campaign to raise money” to support its mission. As stated on their website, this non-profit foundation “provide[s] kids with cancer a higher quality of life for themselves and their families while facing the challenges of cancer.” You can even use the Cancer Fears ME<sup>TM</sup> merchandise to raise money for yourself or anyone you know (child or adult) living with cancer. **Designated Patient Fundraising** is a “ready-made fundraiser”! “This way you and/or your group of supporters don’t need to put together [bake sales] and other time consuming fundraisers. Just fill out the verification form and get your doctor or other caregiver to sign it and you are all set to start receiving monthly commission checks.” Pursuant to the steps listed, the “Cool Kids Campaign sends 25% of every sale directly back to the Designated Patient” and there are no limits on what the money can be used for.

### **Pepsi Refresh (Example, May No Longer be Operational)**

**Website:** <http://www.refresheverything.com/index>

**Description:** “Pepsi is funding amazing ideas that refresh the world. Dream it, submit it, get enough votes and we’ll help make it happen for your community!” Referring to the Pepsi Refresh Project Official Guidelines (<http://www.refresheverything.com/official-application-guidelines>), “the Pepsi Refresh Project is an online grant program which makes available millions of dollars to be granted to projects which are intended to improve communities through an online, democratic voting process (‘Grant Program’). The Grant Program is open to individuals, for profit organizations (which have a maximum of \$5 million in annual revenue) and non-profit organizations (which have a maximum of \$15 million in annual revenue) .... ... The Grant Program consists of four categories (1) ARTS & MUSIC; (2) COMMUNITIES; (3) EDUCATION; and (4) THE PEPSI CHALLENGE.” You will be notified of eligibility via e-mail. If your application is posted for voting, make sure to tell all your friends to vote and spread the word because winning a grant can mean up to \$50K in funding for your project. Good Luck!

### **Standbuy**

**Website:** <https://www.standbuy.us/>

**Phone:** CONTACT@STANDBUY.US

**Description:** Standbuy is a start-up focused on hosting online fundraisers for cancer patients exclusively. You can set up fundraisers for yourself or someone else via this site. There is a fee of eight percent of every donation collected by Standbuy for the service they provide, and the recipient is responsible for paying any appropriate taxes on the money received.

## Pediatric Cancer Research Fundraising Organizations & Ideas

### Arms Wide Open Childhood Cancer Foundation

**Website:** <http://awoccf.org/>

**Address:** Arms Wide Open, P.O. Box 258, Marlboro, NJ 07746

**Contact Info:** 732-904-2799 or [dena@awoccf.org](mailto:dena@awoccf.org) for the NJ/NY chapter or 408-396-8112 or [carmen@awoccf.org](mailto:carmen@awoccf.org) for the CA chapter

**Description:** Expressed on their site, the Sherwoods, “recognizing that children should not be viewed as a profit but, rather, our investment, founded Arms Wide Open,” a registered 501(c)3 publicly supported non-profit organization, following the neuroblastoma diagnosis of their 13 month old son.

Neuroblastoma is a very aggressive cancer of the sympathetic nervous system that most commonly occurs in infants and children under the age of five. There is no known cure for neuroblastoma, and because it is relatively rare – affecting only approximately 650-700 children in the United States each year – research funding for this “orphan” cancer and more effective treatments is limited. “Only 30% of children diagnosed with this disease will survive,” and those that do will face countless health risks due to the toxicity of today’s treatments. Through its efforts, “Arms Wide Open raises money for alternative therapies and actual treatments these children desperately need in order to survive.” Additionally, “each month AWOCCF provides financial assistance to one family who is suffering financial hardship due to their child’s diagnosis of cancer [and] ... hosts the Women’s Integrative Wellness Night at the Ronald McDonald House NYC.”

### Alex's Lemonade Stand

**Website:** <http://www.alexslemonade.org/>

**Address:** Alex's Lemonade Stand Foundation, 333 E. Lancaster Ave., #414, Wynnewood, PA 19096

**Contact Info:** 866-333-1213 or 610-649-3034

**Description:** As stated at <http://www.alexslemonade.org/>, “Alex’s Lemonade Stand Foundation (ALSF) shares the vision of its founder and creator, Alexandra ‘Alex’ Scott—a cure for all children with cancer.” This determined child was diagnosed with childhood cancer before her first birthday. When she was four, she set up a front-yard lemonade stand to give the money raised to doctors to help them find a cure. “While bravely fighting her own cancer, Alex continued to set up lemonade stands every year. As news spread of the remarkable girl so dedicated to helping other sick children, people everywhere were inspired to start their own lemonade stands—donating the proceeds to her cause.” The mission of ALSF is simple: “to raise money for and awareness of childhood cancer causes—especially research into new treatments and cures—and to encourage and empower others, especially children, to get involved and make a difference for children with cancer.” ALSF also hosts Childhood Cancer Symposia annually and funds pediatric oncology nursing research and grants designed to improve the quality of life and care as children battle cancer.

### American Cancer Society

**Website:** [www.cancer.org](http://www.cancer.org)

**Phone:** 800-227-2345

**Description:** Reflected at [www.cancer.org](http://www.cancer.org), “together with [their] millions of supporters, the American Cancer Society (ACS) saves lives and creates a world with less cancer and more birthdays by helping people stay well, helping people get well, by finding cures, and by fighting back. The American Cancer Society is a nationwide, community-based voluntary health organization dedicated to eliminating cancer

as a major health problem. Headquartered in Atlanta, Georgia, the ACS has twelve chartered Divisions, more than 900 local offices nationwide, and a presence in more than 5,100 communities.”

“The American Cancer Society is the largest non-governmental funder of cancer research in the United States, spending approximately \$130 million each year to work to find cures. [They] fund both external research projects through grants and scholarships as well as conduct [their] research into cancer epidemiology, surveillance, and health policy. [They] fund beginning researchers with cutting-edge ideas early in their careers -- 46 of whom have gone on to win the Nobel Prize, the highest accolade in scientific achievement.” Visit their site to find resources in your area.

At times the American Cancer Society has come under fire for not supporting childhood cancers enough. Do your own research to form an educated opinion.

### **American Childhood Cancer Organization (formerly the Candlelighters' Childhood Cancer Foundation):**

**Website:** <http://www.acco.org/Home.aspx>

**Address:** American Childhood Cancer Organization, National Office, P.O. Box 498, Kensington MD 20895-0498

**Phone:** 855-858-2226

**Description:** According to their website, the “American Childhood Cancer Organization (ACCO) began in 1970 by a group of parents whose children had been diagnosed with cancer. They came together to lobby for more research, and to support each other through the diagnosis and treatment of this life threatening disease at a time when very few children survived. Today, ACCO is one of the largest grassroots, national organizations dedicated to improving the lives of children and adolescents with cancer and their families. [They] are strong advocates for our families in Washington D.C., [they] produce the highest quality materials on childhood cancer, and [they] have over 40 local affiliate organizations across the country providing direct services to the families in their communities.” They support research and provide online support groups through Inspire.com and list servers. Additionally, they offer books for children and families who are dealing with childhood cancer, and childhood cancer guide publications, and other free books. (<http://www.acco.org/Information/Resources/Books.aspx>)

### **Band of Parents**

**Website:** <http://www.bandofparents.org/>

**Address:** Band of Parents, PO Box 335, Dewittville, NY 14728

**Contact Info:** [info@bandofparents.org](mailto:info@bandofparents.org), or 703-830-1141

**Description:** These are the parents of children diagnosed with a cancer called neuroblastoma, “who want to help further the research and drug development desperately needed to save more children.” As “an ‘orphan’ cancer,” ... “funding from the government [for neuroblastoma] is similarly limited. Time is running out for many of our children – money stands between them and a cure.”

As shown on their website, “as parents, [they] have banded together to increase public awareness about neuroblastoma and to raise funds for the development of novel therapies. [They] are working in partnership with a talented and dedicated team of doctors at Memorial Sloan-Kettering Cancer Center (MSKCC), who are fighting to save their children from this deadly disease.”

### **Battle4aCure**

**Website:** <http://www.battle4acure.org/>

**Contact Info:** [battle4acure@gmail.com](mailto:battle4acure@gmail.com)

**Description:** Battle4aCure's site discusses how they "raise funds for scientific research and clinical trials to discover advanced treatments for childhood cancers and to potentially find a cure. [They] are dedicated to encouraging citizens to raise awareness and money for childhood cancer until a cure is found. [They] not only want to provide money to restore the financial burden, [they] want to give back Hope to the children and families affected by childhood cancer- the No. 1 disease killer of children." Additionally, they ship out Hope boxes to children with cancer, free of charge.

### **Bear Necessities Pediatric Cancer Foundation**

**Website:** [www.bearnecessities.org](http://www.bearnecessities.org)

**Address:** 55 West Wacker Drive, Suite 1100 Chicago, IL 60601

**Phone:** 312-214-1200

**Description:** Visit [www.bearnecessities.org](http://www.bearnecessities.org) to learn that "Bear Necessities Pediatric Cancer Foundation is a national organization dedicated to eliminating pediatric cancer and providing hope and support to those who are touched by it. [Their] mission is carried out through three unique programs which include the: Bear Hugs Program, Bear Discoveries and Bear Empowerment."

- Bear Hugs Program – "A Bear Hug is a customized experience that brightens the life of a child [(ages 0-19)] going through cancer" and "provides immediate family support for financial burden and essential needs." This is for children being treated at one of the nine major Chicago area hospitals with pediatric oncology departments.
- Bear Discoveries – "Medical research grants awarded nationwide primarily to junior investigative researchers who are making meaningful advancements towards a cure and therapies for pediatric cancers."
- Bear Empowerment – "Support service grants awarded across the nation to pediatric oncology facilities and organizations for programs that directly impact patients, their families and hospital facilities."

### **Children's Cancer Association**

**Website:** <http://www.joyrx.org/>

**Description:** According to their site, the "Children's Cancer Association (CCA) offers award-winning programs and resources to seriously ill children (from birth to 18), their families and the medical professionals who care for them. Every program and resource [they] offer is available to seriously ill children and families that live or seek treatment in Oregon and SW Washington and many of our resources are also available to children, families and medical professionals nationwide."

### **Children's Cancer Research Fund**

**Website:** <http://www.childrenscancer.org/>

**Contact Info:** 1-888-422-7348, [webmaster@childrenscancer.org](mailto:webmaster@childrenscancer.org), or Children's Cancer Research Fund, 7301 Ohms Lane, Suite 460, Minneapolis, MN 55439

**Description:** This organization provides information for families and friends of those with childhood cancers on research, cures and survivorship. Additionally they offer information to those interested in critical research. Their site explains that they "invest in lifesaving, leading-edge research in the prevention, diagnosis, treatment, and cure of childhood cancers and blood-related disorders." Their

research focuses are leukemia, brain tumors, sarcoma, genetic disease, cancer survivorship, and the causes of cancer.

### **Cookies for Kids' Cancer**

**Website:** <http://www.cookiesforkidscancer.org/>

**Address:** Cookies for Kids' Cancer, 31 Hoffmans Crossing Rd., Califon, NJ 07830

**Contact Info:** info@cookiesforkidscancer.org or 888-978-5313 or

[http://www.cookiesforkidscancer.org/ContactUs\\_a/144.htm](http://www.cookiesforkidscancer.org/ContactUs_a/144.htm) for more options

**Description:** Expressed on their site, "Cookies for Kids' Cancer, a 501(c)3 nonprofit, was founded by parents inspired by their son Liam's battle with cancer. They were shocked to learn that the main reason over 25% of kids diagnosed with cancer do not survive is because of a lack of effective therapies. And the reason for the lack of therapies was very simple: lack of funding. They pledged to support the development of new and better treatments by giving people a simple way to get involved."

You can "make a difference by joining the mission to find a cure for pediatric cancer. There are many ways to support Cookies for Kids' Cancer. Hosting a bake sale is a sweet and simple way for people everywhere to get involved in the fight against pediatric cancer. Send our cookies for birthdays, anniversaries, or just because."

"You don't have to eat or bake cookies to be a Good Cookie. Other supporters have run marathons, held tag sales, organized golf tournaments, collected spare change, and hosted car washes to support Cookies for Kids' Cancer. [They've] even made it simple to donate online once or once a month with online giving. The ideas are only limited by your imagination. No effort is too small and every penny counts."

"Through The Cookies for Kids' Cancer Foundation, your support and donations will help scientists and top pediatric oncologists at leading Pediatric Cancer Centers accelerate and deepen their investigation into new and less toxic therapies in an all-out effort to save the lives of innocent children.

Your donations can be directed to a specific pediatric cancer or you may simply donate to Cookies for Kids' Cancer's General Fund. Donations made to the General Fund are granted through a peer review process led by the Cookies for Kids' Cancer Medical Advisory Board."

### **Go 4 the Goal**

**Website:** <http://www.go4thegoal.org>

**Address:** Go4theGoal Foundation, P.O. Box 433, Ho-Ho-Kus, NJ 07423

**Contact Info:** PatientRequest@Go4theGoal.org

**Description:** As stated on their site, "Go4theGoal Foundation's unwavering mission is to help make the lives of children affected by cancer as 'normal' as possible by granting personal wishes, providing financial support to them and their families, developing and implementing unique hospital programs and funding Grants for pediatric cancer research." They were a Top Rated Non-Profit for 2012.

### **The Hope Shop**

**Website:** <http://www.thehopeshop.org>

**Description:** To learn about "The Hope Shop [visit this]... online destination ... to enjoy shopping while supporting the fight against cancer. As much as 90 percent of the proceeds on every purchase made at The Hope Shop supports the American Cancer Society in its fight to eliminate cancer and create a world

with more birthdays by helping people stay well, helping people get well, by finding cures, and by fighting back! ... [Their] products have been carefully designed and selected to provide inspirational messages that represent the hope that one day our world will be cancer-free."

Note that "the Hope Shop supports the work of the American Cancer Society in New York and New Jersey [, and that they have a] sister online store, the ACS Gift Shop," (<http://www.acsgiftshop.com/>).

### **Hugs for Brady**

**Website:** [www.hugsforbrady.org](http://www.hugsforbrady.org)

**Address:** Hugs for Brady Foundation, 4 Quentin Road, Kendall Park, NJ 08824

**Contact Info:** [mwells@hugsforbrady.org](mailto:mwells@hugsforbrady.org) or <http://www.hugsforbrady.org/Contact.html>

**Description:** As stated on their site, "[their] goal is simple, to help in any and every way possible to ease the pain of the children and their families who have cancer. [They] pledge that every dollar donated will be spent [pursuing] a cure for pediatric cancer." Their non-profit organization serves people of all races, creeds, and religions. They do not discriminate. They merely support all causes concerning pediatric cancer. "[Their] ultimate goal is to eradicate pediatric cancer, and [they] will not rest until pediatric cancers of all types are a forgotten nightmare."

### **Journey 4 A Cure**

**Website:** <http://www.journey4acure.org/>

**Contact Info:** <http://www.journey4acure.org/contact-us/>

**Description:** To learn more about this organization's mission and objectives, access their page. There you will see that "Journey 4 A Cure is a Pediatric Cancer foundation committed to enhancing the lives of children and families currently battling cancer while increasing awareness about the realities of pediatric cancer." Their objectives are to: "Enhance the quality of life for children currently undergoing cancer treatment. Encourage the families of children currently undergoing cancer treatment. Enable cutting-edge pediatric cancer research. [And, to e]ducate the community about the realities of pediatric cancer and encourage public policy reform."

### **LIVESTRONG (formerly the Lance Armstrong Foundation)**

**Website:** [www.livestrong.org](http://www.livestrong.org)

**Contact Info:** 877-236-8820, or for cancer support call LIVESTRONG at 855-220-7777

**Description:** According to [www.livestrong.org](http://www.livestrong.org), "[they] look at the experiences of the cancer community, find problems and develop solutions. Then they roll them out to help more people in more situations." To ensure their actions are fruitful, they try to "influence public policy." In the past they hosted global cancer summits. Additionally, by collaborating "with the Centers for Disease Control and Prevention, LIVESTRONG charts a course for the public health community to address cancer survivorship."

LIVESTRONG offers a variety of programs, including those at school "to raise cancer awareness[.] LIVESTRONG challenges advocates, educators, parents and others to get students involved in the fight against cancer." "LIVESTRONG has also joined forces with the YMCA to support people affected by cancer in reaching their health and wellness goals." LIVESTRONG has a Young Adult Alliance as well, which is "a coalition of organizations dedicated to improving survival rates and quality of life for young adults with cancer."

## **The Leukemia & Lymphoma Society**

**Website:** [www.lls.org](http://www.lls.org)

**Contact Info:** For general inquiries, you can use their online contact form ([http://www.lls.org/#/aboutlls/contactus/contactus\\_form/](http://www.lls.org/#/aboutlls/contactus/contactus_form/)) or call 914-949-5213

**Description:** For information on leukemia and/or lymphoma, check out the Leukemia & Lymphoma Society (LLS)'s website. There you will discover that their mission is to "cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families. LLS is the world's largest voluntary health agency dedicated to blood cancer. LLS funds lifesaving blood cancer research around the world and provides free information and support services." They raise money through year-long events and on donations in support of these goals.

## **Make Some Noise: Cure Kids Cancer Foundation**

**Website:** <http://www.makenoise4kids.org>

**Address:** Make Some Noise Cure Kids Cancer Foundation, P.O. Box 9210, Morristown, NJ 07963-9210

**Contact Info:** [info@makenoise4kids.org](mailto:info@makenoise4kids.org) or 973-656-1111

**Description:** The Make Some Noise: Cure Kids Cancer Foundation is cancer kid-initiated organization created "to fund pediatric cancer research." Their site delivers stories of the inspiring founder, Malcolm, and other cancer heroes battling various forms of the disease. They sponsor a variety of events encouraging local participation and childhood cancer awareness; as well as offering ideas for hosting your own events. To make it easier, they provide a link to their "online fundraising event service" (<http://www.firstgiving.com/makesomenoise/fundraisers>). "The Make Some Noise Foundation aligns itself with [CureSearch](#), which is the primary fundraiser for COG. The designation of funds to various research facilities is cancer specific and based on the foundation's annual evaluation of the latest research."

## **National Cancer Institute**

**Website:** <http://www.cancer.gov>

**Description:** Reflected on their site, "the NCI, established under the National Cancer Institute Act of 1937, is the Federal Government's principal agency for cancer research and training. ... Over the years, legislative amendments have maintained the NCI authorities and responsibilities and added new information dissemination mandates as well as a requirement to assess the incorporation of state-of-the-art cancer treatments into clinical practice. The National Cancer Institute coordinates the National Cancer Program, which conducts and supports research, training, health information dissemination, and other programs with respect to the cause, diagnosis, prevention, and treatment of cancer, rehabilitation from cancer, and the continuing care of cancer patients and the families of cancer patients." Go to <http://www.cancer.gov> to gather information on cancer topics, clinical trials, cancer statistics and research and funding.

## **Grief Counseling & Support**

If the unthinkable happens, your family may need the support of professionals. In addition to religious advisors and hospital social workers, you can consider these grief programs.

## Cancer Support Community (formerly Gilda's Club)

**Website:** <http://cancersupportcommunity.org>

**Phone:** 202-659-9709 or 888-793-9355

**Description:** Announced on their site, as of Jun 2011, "The Wellness Community and Gilda's Club Worldwide officially merged to become the Cancer Support Community (CSC). ... By helping to complete the cancer care plan, CSC optimizes patient care by providing essential, but often overlooked, services including support groups, counseling, education and healthy lifestyle programs. Today, CSC provides the highest quality emotional and social support through a network of more than 50 local affiliates, 100 satellite locations and online. To find a community-based center in your area, visit <http://www.cancersupportcommunity.org/MainMenu/Cancer-Support/Find-a-Local-Program>."

## Good Grief

**Website:** <http://good-grief.org/>

**Address:** 38 Elm Street, Morristown, NJ 07960

**Contact Info:** 908-522-1999, 609-498-6674 or [info@good-grief.org](mailto:info@good-grief.org)

**Description:** When you need help working through the grieving process, you can visit the Good Grief site. There, you will see the mission of this group is to "normalize grief in our communities through education, advocacy, and year-round [peer-] support group programs for grieving children, teens and adults. [They] provide services to children, teens and young adults who have lost a parent or sibling to death. [They] also provide services for the children's surviving parent(s) or caretaker."

This is a "safe and caring community where New Jersey's children and families come to heal. ... Through [their] support center and workshops [they] help children during the difficult times of their lives and offer support and guidance to the adults in their lives."

"Orientations are required for families who wish to participate in Good Grief, and are arranged by appointment on an individual basis for each family [<http://good-grief.org/for-families/family-orientationf>]. Orientations are generally held on weekdays in the late afternoon and early evening, though other times can be arranged if necessary. Please call the Good Grief office and speak with a Family Coordinator ... if you would like to schedule an orientation for your family." Reading through the materials online will set your expectations for the visit.

## Noogieland

**Website:** <http://gildasclubsouthjersey.org/noogieland/> or  
<http://www.gildasclubnyc.org/Membership/Noogieland.html>

**Address:** Gilda's Club South Jersey, 700 New Road, Linwood, NJ 08221 or Manhattan Clubhouse, 195 West Houston Street, New York, NY 10014, as well as other locations

**Phone:** 609-926-2699 or 212-647-9700 for the above places

**Description:** Part of what was formerly known as Gilda's Club; Noogieland is a place where children and teens (various ages) who have a loved one with cancer, have cancer themselves or have experienced a loss due to cancer can gather for support.

The South Jersey location offers the following for ages 3 to 14:

- “Noogie Nights– Cancer support through creative play while parents/caregivers attend adult groups or activities.
- Fun Fridays & Super Saturdays– Twice a month designed for the whole family. Includes a family meal prepared by our Noogieland Chef & volunteers, ‘Small Talk’ for the kids & ‘Big Talk’ for parents/guardians.
- NoogieFest– Halloween party in the clubhouse. Food, fun, music & prizes for all our Noogieland families!
- Camp Sparkle– A week long summer camp full of cancer support, education & fun for our Noogieland members!
- Tween Group– monthly support group for ages 12-14.”

Offerings in NYC are similar. Visit the website of the Club nearest you to see what programs are offered for what age groups. Many child/teen activities are scheduled at the same time as adult lectures and support groups “so that support is available for the whole family.”

## Rainbows

**Website:** <http://www.rainbows.org/>

**Address:** 1360 Hamilton Parkway, Itasca, IL 60143

**Contact Info:** 847-952-1770, 800-266-3206 or online at <http://www.rainbows.org/contact.html>

**Description:** As stated on their site, “Rainbows is the largest international children’s charity dedicated solely to helping youth successfully navigate the very difficult grief process, including support for siblings experiencing grief and loss. Every day, children are touched by emotional suffering caused by a death, divorce, deployment of a family member, incarceration of a loved one, or any of a multitude of significant event traumas including natural or manmade disasters. And, while a few children are resilient, we know that most do not bounce back without help. Children need guidance and compassion to prevent a loss event from literally defining their lives through later destructive choices. In fact, research proves that unresolved grief leaves kids vulnerable to major at-risk behaviors.”

“Rainbows provides Facilitator Training for volunteers and age-directed curricula for children and teens ages 4 – 18 who may face a myriad of losses. ... Each curricula edition incorporates specific program objectives and organizational goals that will result in immediate and long-term benefits. They are:

- To develop and strengthen problem-solving and coping skills and appropriate behavior and anger management
- To improve school attendance and academic performance
- To alleviate depression and anxiety
- To reduce emotional pain and suffering of children and teens
- To help children and youth who have experienced traumatic changes in their families improve communication in their family and peer relationships
- To prevent destructive behaviors such as involvement with gangs, alcohol and drug abuse, adolescent pregnancies, and other at-risk behaviors.”

## **Quality Of Life Programs**

When your life changes, sometimes it's the little things that people do for you that make coping a bit easier. A Child Life Specialist, a care package, a personalized wig fitting, a special photograph session, or a way to communicate with friends and family just might bring a smile to your child's face. Here are some organizations that specialize in these services.

### **Battling Buddies (Comfort for Children with Cancer)**

**Website:** <https://www.facebook.com/pages/Battling-Buddies-Comfort-for-Children-with-Cancer/228052250566201>

**Contact Info:** Send a message via their Facebook page.

**Description:** According to its organizer, "Sometimes just a small gesture from a stranger can give a child all the strength that they need to hold on." She sends Scentsy Buddies to children battling cancer, or other assorted gifts. Please note, this is a Facebook page and you need to be a registered user to access it.

### **The Blanket Fairy**

**Website:** <http://theblanketfairy.weebly.com/>

**Contact Info:** <http://theblanketfairy.weebly.com/fairy-care-packages.html> for a care package and <http://theblanketfairy.weebly.com/ways-you-can-help.html> to reach her

**Description:** The Blanket Fairy is a woman who was moved by the story of a child with cancer who was separated from her family during treatment. The Blanket Fairy sends out blankets and other care package items (pajamas, t-shirts, etc.) to these children to comfort them. This organization offers willing volunteers many ways to help, including making blankets or sponsoring a child for their Christmas Hope in July and December programs.

### **Butterfly Kisses Care Baskets**

**Website:** <http://www.butterflykissescarebaskets.com/>

**Contact Info:** <http://www.butterflykissescarebaskets.com/contact-us/>

**Description:** In addition to raising awareness year-round, Butterfly Kisses creates photo collages of ill children and their families to create cherished mementos of their time together. Additionally, their site mentions how they "send each child and their siblings a personalized, small care box filled with small goodies for them to enjoy! And for local children [near their offices in North Carolina, they] provide special care baskets with toys, gifts, and opportunities for memory-making family experiences."

### **Cakes Against Cancer**

**Website:** <http://www.cakesagainstcancerforkids.org/>

**Contact Info:** to submit your child's name for a cake: [grw@cakesagainstcancerforkids.org](mailto:grw@cakesagainstcancerforkids.org), for information: [info@cakesagainstcancerforkids.org](mailto:info@cakesagainstcancerforkids.org), to volunteer: [volunteer@cakesagainstcancerforkids.org](mailto:volunteer@cakesagainstcancerforkids.org), or to become a Gold Ribbon Baker: [grb@cakesagainstcancerforkids.org](mailto:grb@cakesagainstcancerforkids.org).

**Description:** This group of bakers recognizes the bravery of children with cancer by providing them with designer cakes for their birthday or special events. If you are interested, you need to give them plenty of notice because the Cakes Against Cancer volunteer baker will reach out six weeks before the event to discuss the child's wishes for the cake design.

### **The Cancer Card XChange**

**Website:** <http://www.cancercardxchange.org/>

**Contact Info:** [info@cancercardxchange.org](mailto:info@cancercardxchange.org) or The Cancer Card Xchange, PO Box 1004, Collierville, TN 38027

**Description:** The Cancer Card Xchange brings smiles to cancer patients by simply sending them gift cards that they can use to buy whatever they need or want. These include store, dining, supermarket gift cards or gift cards sponsored by various credit card companies.

### **Cancer Secret Angel Project**

**Website:** <https://www.facebook.com/pages/Cancers-Secret-Angel-Project/298493440174406>

**Contact Info:** Send a message via their Facebook page.

**Description:** This project was created by a special person to help people affected by cancer following her own cancer diagnosis and treatment. She creates personalized gift baskets from donated items and ships them to people, including children, just to brighten their day and make them smile. Please note, this is a Facebook page and you need to be a registered user to access it.

### **Cancer Stinks Children's Foundation**

**Website:** <http://www.cancer-stinks.com/>

**Contact Info:** [cancerstinks6709@gmail.com](mailto:cancerstinks6709@gmail.com), Cancer Stinks Children's Foundation, P.O. Box 112, Berkeley Heights, NJ 07922 or <http://www.cancer-stinks.com/Cancer-Stinks-Contact-Us/>

**Description:** This foundation was created by Nicholas, a nine year old cancer survivor. Remembering what it was like to spend nights in the hospital during his fight, he vowed to "make a change in the world." His foundation offers "Nights of Love," care packages to other children with cancer. The packages include a nightlight, a teddy bear to hug and a photo frame to see loved ones while you are separated from family and friends. According to their website, 'each item in the package was personally chosen by Nicholas to bring comfort and security, and lessen those feelings of fear a child may have when they spend night after night in the hospital.'

### **Chemo Angels**

**Website:** <http://chemoangels.net/>

**Contact Info:** [chemoangels@prodigy.net](mailto:chemoangels@prodigy.net) or Chemo Angels, P.O. Box 1971, Julian, CA 92036, USA

**Description:** Chemo Angels supports people with cancer by providing helpful information and cancer related resources. Additionally, they match patients who are going through chemotherapy with "Angels" who cheer on the patient and provide them with encouraging notes, cards and small gifts on occasion. Contact them if you are looking for an angel, or want to be one (if you are 25 years or older).

### **Cherished Creations**

**Website:** <http://www.cherishedcreations.com/>

**Address:** 343 Snyder Avenue, Berkeley Heights, NJ 07922

**Phone:** 908-790-0616

**Description:** Visit [www.cherishedcreations.com](http://www.cherishedcreations.com) to learn that "Cherished Creations, Inc. is a 501-C-3 Non-Profit Corporation whose mission is to create better lives for seriously-ill children and the

underprivileged.” They accomplish this through a number of programs that you can contact them about for your child:

- “Wish Requests: ‘Fun’ requests for seriously-ill children up to age 21 have included trips to Disney World; celebrity ‘meet-and-greets’; Broadway show and concert tickets with limo; computer systems, and shopping sprees.
- Special Requests: Miscellaneous requests to create better life for seriously ill children who might otherwise not be able to live at home; (e.g.; wheelchair ramps, electrical upgrades to accommodate portable ventilator, air conditioners, uncovered medical equipment).
- Recycled Furniture/Clothing: Collected and distributed at no cost to clients.
- Other: Summer camperships, Christmas Gift Programs; Recycled Computers; Service Awards, Scholarship program with community service requirement, Educational devices for developmentally disabled children.”

### **Childhood Leukemia Foundation**

**Website:** <http://www.clf4kids.org/>

**Contact Info:** 888-CLF-7109 or 732-920-8860, 807 Mantoloking Road, Brick, New Jersey 08723 or <https://www.clf4kids.org/index.php/contact-us>

**Description:** If you have a child battling cancer in need of a smile, go to <http://www.clf4kids.org/> and request a wish basket. If you are far from home and in need of help paying for your calls, request a phone card. If you are in need of help organizing all the information that doctors are giving you, ask them for a Hope Binder. The Childhood Leukemia Foundation is “dedicated to making the treatment process less difficult, both emotionally and physically on child and parent alike, by offering programs that simplify care management strategies as well as those that allow children to mix seamlessly with their surroundings.”

### **Children’s Cancer Recovery Foundation**

**Website:** <http://childrenscancerrecovery.org/>

**Contact Info:** [childrens@cancerrecovery.org](mailto:childrens@cancerrecovery.org), 800-238-6479 or P. O. Box 238, Hershey, PA 17033

**Description:** Because this organization has a national presence, the Children’s Cancer Recovery Foundation is able to help in large and small communities alike. They assist with the financial and emotional hardships that accompany a childhood cancer diagnosis. Through their Bear-Able Gift Program, they are the largest supplier of gifts to children with cancer in North America delivering board games, toys, puzzles, teddy bears and crafts. They assist families in financial straits with emergency bridge payments so that each child has a “warm, safe place to call home while recovering from cancer.” This group also runs a Camp Scholarship Program for children in remission to go to the camp of their choosing to reconnect with friends.

### **Cody’s Wheels of Hope**

**Website:** <http://www.cwoh.org/>

**Contact Info:** 814-460-8228, [info@cwoh.org](mailto:info@cwoh.org) or Cody’s Wheels of Hope, Inc., P.O. Box 8735, Erie, PA 16505

**Description:** This non-profit charity was started as a memorial to Cody Scott Filson who earned his wings shortly before his 5<sup>th</sup> birthday. In his honor, they provide bicycles or other wheeled toys to

children under 15 years of age with life-threatening illnesses, whose families otherwise couldn't afford one. Contact them if you know of a child who would appreciate such a gift.

### **Cool Kids Campaign**

**Website:** <http://www.coolkidscampaign.org/>

**Phone:** 410-560-1770

**Description:** Check out <http://www.coolkidscampaign.org/> for more information on the Cool Kids Campaign. You will find out that they "provide kids with cancer a higher quality of life for themselves and their families while facing the challenges of cancer." From the beginning, they have always made it their goal to have a direct impact on the children fighting cancer, because kids are kids regardless if they are sick or healthy. Every kid wants to feel cool even if they don't feel well.

As they decide how to help these kids and best use their donated dollars, they make their decisions based on whether their actions will directly affect a child and make them forget, at least for a little while, that they are fighting for their lives. Keep in mind that over time, their offerings may change.

To be eligible for any of the Cool Kids Campaign programs below please complete their application provided online (<http://www.coolkidscampaign.org/docs/Cool-Kids-Campaign-Program-Application.pdf>) and ask your hospital social worker for a referral:

- Cool Kids Care Packages –Volunteers gather "care package items that reflect each child's specific interests, then assemble and mail the packages to their homes as a welcome surprise."
- Cool Kids Connection –“Family [members and children living with cancer] are invited to submit [articles], poems, artwork, photography, and/or anything that reflects who they are and how they feel about the experience” to this quarterly newspaper “delivered to 130 pediatric oncology hospitals across the country.”
- Cool Kids Learning Center – This Baltimore, Maryland based, free of charge initiative offers “individualized tutoring, group activities, and ‘Mommy and Me’ for [preschool age] oncology patients ... [so patients can have a place where they belong and] continue a normal childhood ... alongside peers with similar experiences.”
- Cancer Fears ME™ – The Cool Kids Campaign uses this ‘trademarked slogan on a line of merchandise which helps fund their programs. Patients are also able to utilize the line of merchandise as a fundraiser for themselves through their Designated Patient Fundraising – this gives back to families 25% of sales, which they can use to cover some of their cancer related expenses.’
- Adventures in Baltimore – Courtesy of 1st Mariner Arena in Baltimore, Cool Kids families are given the opportunity to enjoy various family entertainment throughout the year, including participation with the Major League Baseball Players Association’s Buses for Baseball program (<http://mlb.mlb.com/pa/trust/buses.jsp>).

### **Flashes of Hope**

**Website:** <http://www.flashesofhope.org/> or <http://www.thevaleriefund.org/programs/flashes.php>

**Contact Info:** <http://www.flashesofhope.org/contact>

**Description:** The Valerie Fund summarizes it very well on their site: “Flashes of Hope (FOH) is a Cleveland-based non-profit organization dedicated to creating uplifting photographic portraits of children fighting cancer and other life-threatening illnesses. Classic black and white portraits, taken by volunteer award-winning photographers, help sick children feel better about their changing appearance by celebrating it! ... About 4-6 weeks after the photo shoot the families receive a beautiful portrait gift package, including a leather portfolio with two 8x10 portraits, a stack of 4x6 proofs, and a CD with digital copies of all the images. A release letter from the photographer allows the families to take the CD to any photo processor to have copies made. The gift packages, as well as the photo session, are all free to the families because all participating photographers, stylists, and Valerie Fund photo shoot organizers volunteer their time and services.” If your child is not being treated at one of the Valerie Fund Children’s Center, refer <http://www.flashesofhope.org> for additional details and a local shoot. Valerie Fund patients should contact their social workers to inquire about this service.

### **Halos For Angels, Inc.**

**Website:** <http://halosforangelsinc.com>

**Address:** PO Box 415, Florham Park, NJ 07932

**Phone:** 973-845-9636

**Description:** Their founder organized Halos For Angels, Inc. in January, 2010 following a breast cancer diagnosis. Although she is currently in remission, she remembers all the local volunteers who helped with her daily chores and wanted to create an organization to aids families with “temporary relief, comfort and support [due to] sudden tragedy.” As said by their founder, the “purpose of Halos For Angels is to nurture its communities ‘well-being’ by extending to its family members ... help with the day-to-day responsibilities.” These include “transportation services, shopping trips, child care, and daily meals.” Halos For Angels, Inc. works closely with each individual and/or family to fulfill their distinctive needs.

### **Handicap License Plates**

**Website:** [http://www.state.nj.us/mvc/Vehicle/handicapped\\_Apply.htm](http://www.state.nj.us/mvc/Vehicle/handicapped_Apply.htm)

**Contact Info:** Select a contact option at <http://www.state.nj.us/mvc/About/index.htm>

**Description:** If your child experiences a loss of mobility because of their illness, you can apply for temporary or permanent handicapped licenses plates or placards to help you get around easier. Although recapped here, detailed instructions are available online at [http://www.state.nj.us/mvc/pdf/Vehicles/HDC\\_Placard\\_Instructions.pdf](http://www.state.nj.us/mvc/pdf/Vehicles/HDC_Placard_Instructions.pdf). Handicapped plates will only be issued to one vehicle – registered either to the qualified (i.e., disabled) person or to one family member who provides transportation for your child. “A placard in conjunction with a [Disabled Person] Identification Card can be used in any vehicle you ride in, whether or not you own it.”

According to the NJ Motor Vehicle Commission’s site, you can obtain these plates by following the steps below:

“To apply for plates or a placard, complete the Application for Vehicle License Plates and/or Placards [available at their website ([http://www.state.nj.us/mvc/pdf/Vehicles/HDC\\_Placard\\_Application.pdf](http://www.state.nj.us/mvc/pdf/Vehicles/HDC_Placard_Application.pdf)),

along with your doctor,] and visit your local MVC agency or mail the application to: NJMVC Special Plate Unit, PO Box 015, Trenton, NJ 08666-0015.

A copy of the vehicle registration must be included with plate applications. Refer to the application checklist [available at their website] to avoid processing delays. There is no additional charge for handicapped plates. Applicants without a license or non-driver identification card must prove identity by passing the 6 Point ID Verification."

"To apply for a temporary parking placard:

- Go to your local police station to get an application. You must have your doctor certify that you need the placard.
- Return the completed application to the police department with a \$4 fee payable to Motor Vehicle Commission.
- Upon payment, the police department will issue your temporary placard.
- Temporary placards are issued for six months, with one six-month renewal allowed."

### **Healing Spaces**

**Website:** <http://www.healingspaces.org/>

**Contact Info:** info@healingspaces.org or Healing Spaces Inc., P.O. Box 2603, Wayne, NJ 07470 or 973-879-3683

**Description:** Check out <http://www.healingspaces.org/> to learn about Healing Spaces. "[Their] mission is to warm the hearts and bring joy to children with cancer and other serious illnesses by creating a unique healing environment in their home that minimizes the stress of hospitalization and gives them their own space to recover. Utilizing the assistance of designers, artisans, painters, carpenters, electricians and other volunteers, along with input from the child, [they] transform their bedroom into a personalized environment, complete with healing elements specific to their individual needs. [They] bring smiles and happiness to as many of children as [they] can is [their] goal. [They] are passionate about the potential of Healing Spaces and [they] look forward to expanding throughout the New Jersey community and beyond."

### **Hopecam**

**Website:** <http://www.hopecam.org>

**Contact Info:** 703-620-2555, ext. 101, [info@hopecam.org](mailto:info@hopecam.org), or <http://www.hopecam.org/contact>

**Description:** Hopecam is a wonderful use of Skype technology (<http://www.skype.com>) that you should consider if your child is school-aged. "[It] helps connect homebound children undergoing treatment for cancer, and other life-threatening illnesses with their friends at school using [shared, free equipment:] laptops, high speed internet connections and web cameras [as needed]. ... Recognizing the critical need for socialization with their friends and classmates, Hopecam seeks to bridge the lonely divide between homebound children and their friends at school during this frightening time. Staying connected to school significantly reduces the stress of re-entry when treatment is completed and children resume a normal life." They work closely with the schools' personnel to make sure that the Hopecam gets set up as quickly and easily as possible. To apply, fill out their online application (<http://www.hopecam.org/apply>) at their website; and, feel free to ask your friends and family to donate to this organization to ensure that others can also benefit from this service.

### **Icing Smiles Inc.**

**Website:** <http://www.icingsmiles.org/>

**Contact Info:** 443-326-3569, info@icingsmiles.org, 4725 Dorsey Hall Drive, Suite A-807, Ellicott City, MD 21042

**Description:** This wonderful non-profit organization of bakers brings smiles to children with life-threatening medical conditions in the form of cakes. They serve ill children, 18 years or younger, within two years of their last treatment, or siblings of angels who have earned their wings in the same timeframe. They offer two types of cakes, but all are free of charge regardless of financial need. Their 'dream cakes' are three-dimensional carved wonders so you are limited to only one, while their 'Fun cakes' are not as difficult to make so they don't have the same limit. If you are interested, contact them and be prepared to share some evidence of your child's illness (CaringBridge site or Make-a-Wish affiliation).

### **Joshua Cares**

**Website:** <http://joshuacares.weebly.com/>

**Contact Info:** [joshua.cares@yahoo.com](mailto:joshua.cares@yahoo.com), 615-779-4934 or Joshua Cares, C/O Seki Tyree, 1148 Panama Street, Memphis TN 38122

**Description:** Joshua's mother ensured that he was never sad during his treatment for medulloblastoma by placing gifts in his mailbox every day. After they declared him cancer-free, Joshua asked to send gifts and inspirational messages to other children around the world who are battling terminal illnesses, just to make them smile. Visit their site or find them on Facebook to send a gift box to a child with cancer.

### **Joy Jars®**

**Website:** <http://www.negu.org/joy-jars/>

**Contact Info:** 1-888-648-6348 or 22521 Avenida Empresa, Suite 112, Rancho Santa Margarita, CA 92688

**Description:** Visit their website to send a Joy Jar® to a child with cancer or other life-threatening illness. These were the idea of Jessie Rees before losing her 10 month courageous cancer battle. Joy Jars® are: "64oz plastic jars filled with new toys & activities, stuffed by love for boys and girls ages 18 and under" that are "100% free to patients and hospitals" used for "empowering kids in 50 states and over 125 Children's Hospitals." They don't include "food, lotion, sharp objects or choking items."

### **Keep Kids Connected**

**Website:** <http://www.keepkidsconnected.org/>

**Contact Info:** <http://www.keepkidsconnected.org/contactus.htm>

**Description:** Keep Kids Connected leverages the power of social connections to aid in the healing process. This organization was inspired by social teenager who was diagnosed with lymphoma. A family friend gave her a computer to keep in contact with her friends and family during her treatment and an idea sparked. According to their website, "Her wish is that every kid battling cancer or any life-threatening illness be given a computer so they can stay connected to their family and friends while they go through their treatments. She knows firsthand the power of social healing; how staying in touch with friends can brighten your day and help keep the blues away; it provides a special kind of healing that medicine or doctors can't provide. She wants other kids to experience the power of social healing and help them forget about their illness, or at least make it a little more bearable to go through their treatment." Keep Kids Connected serves children ages 4-18 who are actively being treated for a life-threatening illness.

### **Kick Cancer Overboard**

**Website:** <http://kickcanceroverboard.com/>

**Contact Info:** <http://kickcanceroverboard.com/contact-us/>, [kickit@kickcanceroverboard.org](mailto:kickit@kickcanceroverboard.org), Kick

Cancer Overboard, Drs James Parker Blvd Suite 104, Red Bank, NJ 07701 or 732-758-1990

**Description:** Kick Cancer Overboard is a small start-up charity that sends people dealing with cancer on a free cruise vacation. “Imagine: A cruise ship filled with cancer fighters and survivors, their friends, family and supporters – celebrating life!” They offer cancer patients something to look forward to, and offer a “break for a few days, where the most important question is not how to pay for the next medical bill, but whether to play bingo, get a massage or sing karaoke.” Since they are a small organization, they can’t afford to send everyone on a cruise for free, so, they utilize an application process to select cruise recipients. Visit their website and share the story of how cancer has affected your life to be considered.

### **Kiss the Toad Creations**

**Website:** <http://www.kissthetoadcreations.com/>

**Contact Info:** [info@kissthetoadcreations.com](mailto:info@kissthetoadcreations.com), 925-216-2272 or P.O. BOX 3741, San Ramon, CA 94583

**Description:** This fun organization “encourages and recognizes children who are battling a life-threatening illness by presenting them with an official superhero cape.” They don’t simply mail child the cape. Instead, they host a Superhero Celebration to celebrate their “super-human strength.” These two hour parties are held at Ronald McDonald Houses or similar organizations across the United States during which the child is officially presented with the cape in addition to sweet treats, superhero balloons, fun activities, pictures, gift basket giveaways for parents and more. Sometimes Spiderman, Batman, or Wonder Woman makes an appearance, and of course, there is always a special appearance made by The Toad Princess, who fashioned the cape.

### **Lennon's Smile Box Program**

**Website:** <https://www.facebook.com/pages/Lennons-Smile-Box-Program/326474267395643>

**Contact Info:** Send a message via their Facebook page.

**Description:** According to their page, “This program was started in honor of Lennon Hunt after he lost his battle with Cancer and ALD.... [They] send ‘Lennon’s Smile Boxes’ to children battling cancer across the United States [as] a way of providing them with some cheer and giving them a reason to smile. Lennon loved to smile and his would fill a room with joy and we are hoping to keep his wonderful positive spirit and legacy alive.” Please note, this is a Facebook page and you need to be a registered user to access it.

### **Look Good Feel Better Programs for Teens**

**Website:** <http://www.2bme.org/2bMe.html> or <http://lookgoodfeelbetter.org/programs/programs-for-teens>

**Contact Info:** <http://lookgoodfeelbetter.org/contact>, info@2bme.org, or 800-395-LOOK

**Description:** Keeping a positive attitude helps in the healing process. 2bMe is “A Site for Teens with Cancer. Get the scoop on the non-medical stuff you’re wondering about – from skin and hair to fitness and friends. Now U can deal.” Teens, aged 13-17, who have cancer can access this “non-medical, public service” offered by Look Good Feel Better to “deal with the possible appearance related, social and nutritional side effects of treatment ... through informative, fun [in-hospital] patient sessions and this website.” Check out the site to see if your treatment facility is listed as a host for their sessions.

### **Medi-Monsters**

**Website:** <http://www.medi-monsters.com/>

**Contact Info:** [medimonsters@gmail.com](mailto:medimonsters@gmail.com), via Facebook message or Medi-Monsters, 22 Carl Giles Rd., Glenmora, LA 71433

**Description:** A fellow cancer mom recognized the need for sick children to cling to a treasured toy when they aren't feeling well. In her own words: "Kids LOVE their security objects in the midst of insecurity...during stressful, possibly painful situations." So, she started making Medi-monsters to "gobble up all your fears." She sends these adorable, home-made, felt, stuffed toys to children with illnesses upon request. She only asks that you share some contact information, a CaringBridge or Facebook site (if you have one), and a picture of the child with the toy after you receive it.

### **Monkey In My Chair**

**Website:** <http://www.monkeyinmychair.org/>

**Contact Info:** <http://www.monkeyinmychair.org/site/contact> or 513-772-4888

**Description:** This organization is dedicated to helping children (aged 4 to 11) connect to their classroom while actively undergoing cancer treatments. They provide an actual stuffed monkey that can take the student's place at school; a guidebook for teachers to explain what the cancer patient is going through; and access to "Monkey Message," the online component that enables on-going communication between the patient and the class. All these services are provided at no cost.

### **Packages of Hope**

**Website:** <http://www.packagesofhope.com/>

**Contact Info:** [info@packagesofhope.com](mailto:info@packagesofhope.com) or Packages of Hope, P.O. Box 1062, Selah, WA 98942

**Description:** As a senior in high school, Mikayla Vickers formed Packages of Hope to send care packages to children battling against cancer, including personal deliveries to St. Jude. Her hope is to share moments of joy and comfort with these children while they face the challenges of cancer. If you are a parent of a sick child, you may request a package on her site.

### **Peach Neet Feet**

**Website:** <http://peachsneetfeet.com/>

**Contact Info:** <https://peachsneetfeet.com/contact/>

**Description:** This group of artists paints custom-designed canvas sneakers for children with disabilities or children (5T up to age 18) fighting serious illnesses. Each is a unique work of art personalized "to complement each child's life, interest, and courageous fight" and is donated free of charge just to make them happy and to show their families that they "are supported and strengthened".

### **Songs of Love**

**Website:** <http://www.songsoflove.org/>

**Contact Info:** Songs of Love Foundation, P. O. Box 750809, Forest Hills, NY 11375 or 800-960-SONG

**Description:** Go to <http://www.songsoflove.org/> to request "free, personalized, original songs to uplift children and teens currently facing tough medical, physical or emotional challenges [created by this national non-profit 501(c)(3) organization]. Each CD is professionally produced with lyrics containing the child's name and references to all of his or her favorite activities, things, people, and pets. Songs are written and performed in any language in the musical style that the child likes best (pop, R&B, rap, rock, alternative, etc.), by a variety of talented professionals."

### **Starlight Children's Foundation**

**Website:** [www.starlight.org](http://www.starlight.org)

**Contact Info:** 2049 Century Park East, Suite 4320, Los Angeles, CA 90067 or 310-479-1212

**Description:** According to their site, “for more than 30 years, the Starlight Children’s Foundation has been dedicated to improving the quality of life for children with chronic and life-threatening illnesses and life-altering injuries by providing entertainment, education and family activities that help them cope with the pain, fear and isolation of prolonged illness.”

They understand what families go through when a child is sick, and how important it is to find relief from constant worry and isolation. “[Their] programs have been proven to distract children from their pain, help them better understand and manage their illnesses, and connect families with others facing similar challenges so that no one feels alone.” “Unlike any other charity, Starlight offers a comprehensive menu of outpatient, hospital-based and Web offerings that enable them to provide ongoing support for children and families — from diagnosis through the entire course of medical treatment.”

Programs include: family activities and outings; in-hospital entertainment technology; in-hospital playrooms, kid-friendly treatment rooms and special events; and “educational programming via online interactive games.”

### **Team Keegan**

**Website:** <http://team-keegan.com/>

**Address:** Team Keegan, 3298 W. 16th St., Fremont MI 49412

**Phone:** 231-206-6435

**Description:** Team Keegan sends a “prize box” to kids with cancer (free of charge) so they can reach in and get a prize after every treatment or struggle. Their goal is to keep cancer kids smiling by providing incentives for being brave.

### **Tucker's ToyBox**

**Website:** <http://www.tuckerstoybox.org/>

**Contact Info:** <http://www.tuckerstoybox.org/contact.htm> or

<http://www.tuckerstoybox.org/giftsofencouragement.htm>

**Description:** The Tucker Arnold Foundation was the dying wish of an 11 year old boy who earned his wings after a hard-fought battle with leukemia. He found that being in the hospital wasn’t as awful if he received a new toy to distract him from the boredom and loneliness that he felt. In his memory, they send gifts of encouragement to children with cancer who have been in-patient for a week or more.

### **The Valerie Fund**

**Website:** <http://www.thevaleriefund.org/>

**Address:** The Valerie Fund, 2101 Millburn Avenue, Maplewood, NJ 07040

**Contact Info:** 973-761-0422 or <http://www.thevaleriefund.org/about/contact.php>

**Description:** Many children fighting cancer and blood disorders in New Jersey, New York, and the Philadelphia are being treated at one of the seven Valerie Fund Children’s Centers for Cancer and Blood Disorders. Go to <http://www.thevaleriefund.org/> to learn more about this “not-for-profit organization established in 1976 in memory of nine-year-old Valerie Goldstein by her parents, Ed and Sue.”

"The Valerie Fund's mission is to provide support for the comprehensive health care of children with cancer and blood disorders." They "provid[e] caring, comprehensive, state-of-the-art outpatient health care to more than 4,000 children and their families each year ... close to their homes." Thanks to the Valerie Fund, families can stay together during treatment and the entire family is cared for, improving their overall quality of life and patient care.

"Families turn to The Valerie Fund because of the unique combination of medical care, counseling, and other services it provides." These families include the ones that compiled this guide, so you can trust that they will help you. Their programs and services include: Child Life Centers, Child Life Specialists, Social Workers, Social Services, Resource Centers, Support Groups, Sibling Workshops, School Re-Entry programs, Transportation/Van programs, Camp Happy Times, the Sickle Cell Program & Initiative, favored access to the Late Effects/LITE Program of The Cancer Institute of New Jersey (CINJ), Flashes of Hope, and a Scholarship Program to attend a variety of institutions, including trade schools, two-year community colleges, and four-year colleges and universities.

### **Washable Wearable Masks**

**Website:** <http://www.etsy.com/shop/janshop12>

**Contact Info:** Send a message to the shop owner via ETSY

**Description:** This ETSY shop creates and sells machine washable double gauze masks so you don't have to worry about germs building up. They are made of "100 percent cotton gauze" in different prints, an inner fabric of "100 percent Tio Tio antibacterial gauze" in a double layer, a flexible plastic wire for the nose section, and a "super soft elastic ... specially made for gauze masks." These are stylish, comfortable and so much better than the paper or hard masks that our kids traditionally have to wear. Note that this is an ETSY shop, so you need to be a member to communicate with this shop owner or make a purchase.

## **Hair Loss Organizations**

### **Girl On the Go!**

**Website:** <http://www.girlonthego.biz/>

**Contact Info:** [wigs@girlonthego.biz](mailto:wigs@girlonthego.biz) or 800-355-6976

**Description:** Girl On the Go! offers private home appointments in parts of New Jersey, New York, Pennsylvania, Connecticut, Massachusetts, Rhode Island, North Carolina, South Carolina, and Wisconsin to fit women with wigs who have hair loss due to cancer, chemotherapy or other reasons "to take the stress out of wig shopping." Visit their site to see if your location is included. If you e-mail them a photo, they will bring a collection of wigs chosen just for your child. Unlike other services listed here, there are fees involved, but many are applied to any purchase that you make.

As said by founder and fellow cancer survivor Sheril Cohen, "One of the most horrific experiences of cancer is losing your hair. While you are making difficult decisions about your treatment plan you may also be facing the reality of hair loss. For many, losing your hair symbolizes a loss of self, a loss of control and the visible confrontation of being ill. You are no longer in control of your appearance. Wearing a 'bad' wig is a public statement that you are sick. But for most, cancer is a very private and personal experience. Shopping for a wig is a difficult experience. From walking into the shop, to waiting for the attendant, it can feel as exposing as trying on a bathing suit in a public parking lot! Girl On the Go! has the solution."

## **Hair Club for Kids**

**Website:** <http://www.hairclub.com/hc-for-kids.php>

**Contact Info:** 800-269-7384 or <http://www.hairclub.com/contact-us.php>

**Description:** As stated on their site, “since 1992, Hair Club has been offering free hair restoration services to children who suffer from diseases where the illness or treatment caused hair loss or alopecia. Hair Club for Kids is a non-profit program funded entirely by Hair Club. It is available, at no charge, to children ages 6-17 years old. With over 95 hair loss centers in the US, Canada, and Puerto Rico, this free service is accessible to every child in need.” Visit them on the web to learn more about hair loss treatments, restoration, replacement, etc.

## **Hats Off For Cancer**

**Website:** <http://hatsoffforcancer.org/>

**Contact Info:** [info@hatsoffforcancer.org](mailto:info@hatsoffforcancer.org), 424-888-HOFC or Hats Off For Cancer or 6200 De Soto Ave #35102, Woodland Hills, CA 91367

**Description:** Hats Off For Cancer collects and donates brand-new hats to children who have lost their hair through cancer treatments. Over the years, this 501 (c) 3 non-profit has distributed over a million hats. Contact them if you would like your child to receive one.

## **Heavenly Hats Foundation™**

**Website:** <http://www.heavenlyhats.com/>

**Contact Info:** 920-362-2668 or [anthony@heavenlyhats.com](mailto:anthony@heavenlyhats.com) or <http://www.heavenlyhats.com/heavenlyhats/contactcommentsquestions/default.asp>

**Description:** The Heavenly Hats Foundation™ was founded as a Wisconsin non-profit corporation by Anthony Leanna, when he was only 10 years old. In his own words, “[his 100% volunteer] program was started to provide brand-new hats for cancer patients and other medical patients who lose their hair due to a disease or the treatment of a disease. Heavenly Hats™ wants to be able to provide hats to individuals and hospitals in order to help the patients feel better about themselves and to give them the extra courage and hope to win their fight. Hair loss during the battle of a disease can be uncomfortable, depressing and at times even a little humiliating. The hat is just a small symbol of hope and love, but my wish is that it will have the power to brighten the patients[’] day so that they can look to the future with a smile.”

They collect and distribute brand new hats, free of charge, to those heroes of all ages who have lost their hair due to a medical condition. If you are interested, fill out their online request form

<http://www.heavenlyhats.com/heavenlyhats/request+a+hat+package/default.asp>.

## **Hugs-U-Wear**

**Website:** <http://www.clf4kids.org/index.php/what-we-do/hugs-u-wear>

**Contact Info:** 888-CLF-7109 or 732-920-8860, Childhood Leukemia Foundation, 807 Mantoloking Road, Brick, New Jersey 08723 or <https://www.clf4kids.org/index.php/contact-us>

**Description:** “When being treated for cancer, one of the biggest social challenges children face is the temporary loss of their hair. Trying to blend in is tough enough sometimes and losing hair, even if only briefly, can make an already trying ordeal, that much more taxing.” If your child experienced hair loss because of cancer, or treatment, reach out to the Childhood Leukemia Foundation at their site.

Hugs-U-Wear are the “thousands of custom made, 100% human hair wigs, combined with kid-friendly hats to children around the country [by CLF].” This is a “national non-profit organization that provides a

myriad of services – totally free of charge - to children battling cancer and their families. [They] work closely with social workers, care providers, families and loved ones to also provide meaningful information, dispensed in a practical manner befitting their challenging lifestyles. [Their] goal is to help children and families living with cancer by assisting them in managing their care and improving the quality of their lives. The Childhood Leukemia Foundation seeks to simplify otherwise taxing responsibilities using programs that are designed to educate and entertain while undergoing treatment.”

If you would like to donate your hair, they accept contributions of at least 10” hair lengths. Please follow their guidelines at <https://www.clf4kids.org/index.php/donate/donate-your-hair> to make sure that your donation helps a child in need.

### **Locks of Love**

**Website:** <http://locksoflove.org/>

**Contact Info:** 888-896-1588 or 561-833-7332, info@locksoflove.org or 234 Southern Blvd., West Palm Beach, FL 33405-2701

**Description:** According to their site, “Locks of Love is a public non-profit organization that provides hairpieces to financially disadvantaged children under age 21 suffering from long-term medical hair loss from any diagnosis. ... Most of [the] children suffer from an autoimmune disorder called alopecia areata. ... Other recipients have been victim to severe burns, endured radiation treatment to the brain stem as a treatment for cancer, or suffer from any number of skin disorders that cause permanent hair loss. ... [Their] mission is to return a sense of self, confidence and normalcy to children suffering from hair loss by utilizing donated ponytails to provide the highest quality hair prosthetics [that would normally retail between \$3.5-6K]. The children receive hair prostheses free of charge or on a sliding scale, based on financial need.” ‘They are not associated or affiliated with any for-profit hair replacement business.’

If you are looking for ways to give back, they also accept hair donations in lengths of at least 10”. The guidelines are posted. If your child is in need of their assistance, fill out the application <http://locksoflove.org/HairPieceApplication.pdf>. Follow the instructions and include the necessary medical, financial and personal documents that they require.

## **New Jersey Organizations**

### **Ashley Lauren Foundation**

**Website:** <http://ashleylaurenfoundation.org>

**Address:** The Ashley Lauren Foundation, 315 Route 34, Suite 135, Colts Neck, NJ 07722 or <http://ashleylaurenfoundation.org/contact-us>

**Phone:** 732-414-1625

**Description:** Visit <http://ashleylaurenfoundation.org> to learn more about this local organization. “[Their] mission is to provide hope and help for NJ children and their families when facing pediatric cancer. ... How [they] help: material assistance; emotional support; financial assistance; parties for the children; birthday and holiday gifts for the children; ...and anything else that is needed.”

### **Emmanuel Cancer Foundation**

**Website:** [www.emmanuelcancer.org/](http://www.emmanuelcancer.org/)

**Address:** ECF Headquarters, 1833 Front Street, Scotch Plains, NJ 07076

**Phone:** 908-322-4323

**Description:** Stated on their site, “the Emmanuel Cancer Foundation (ECF) is committed to being a beacon of light for New Jersey families of children diagnosed with cancer. Through trained professionals and dedicated volunteers, their goal is to replace fear with hope and confusion with balance. ...

Founded in 1983, the ECF serves New Jersey’s children with cancer and their families by providing emotional, material and emergency financial support. ECF kids and their families receive a comprehensive package of:

- Emotional support, counseling, and advocacy services through ECF's team of professional caseworkers.
- Material assistance is made available through the four regional centers. Regional Directors coordinate the collection and distribution of food, toys, new clothes, and household items to families; as well as conducting fundraising efforts for the foundation.
- Emergency financial assistance for families in a crisis situation.”

### **Frances Foundation for Kids Fighting Cancer**

**Website:** <http://www.francesfoundation.net/>

**Address:** The Frances Foundation for Kids Fighting Cancer, Inc., 8 Bryce Road, Holmdel, NJ 07733

**Phone:** 732-410-2383

**Description:** Helping some of the families that contributed to this guide, “The Frances Foundation has a focused, devoted commitment to bring smiles to kids fighting cancer. The 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 again cancer. The Foundation seeks to give compassionately to children and families dealing with extremely difficult physical and emotional challenges. In addition to direct aid to a child or family, The Foundation also supports research aimed to terminate childhood cancers. Helping kids is [their] passion.”

### **Jason’s Dreams for Kids**

**Website:** <http://www.jasonsdreamsforkids.com/>

**Address:** Jason’s Dreams for Kids Foundation, Inc., 20 Monmouth Street, Red Bank, New Jersey 07701

**Phone:** 732-758-0060

**Description:** Contact Jason’s Dreams for Kids at [jasonsdreams@comcast.net](mailto:jasonsdreams@comcast.net) if you know a child suffering from a serious illness who could use a pick-me-up. “[This organization] is devoted to granting [free] wishes to children [in New Jersey] diagnosed with life-threatening illnesses [to enrich their lives with hope, strength and survivorship.] Bringing a little happiness and putting a few smiles on these children’s faces - and hopefully, their parents’ faces - is their goal.” Children can be referred to Jason’s Dreams for Kids, Inc. by physicians, parents, or even other children.

## Wish Granting Organizations

### Make-A-Wish Foundation of New Jersey (also located throughout the US)

**Website:** <http://nj.wish.org/>

**Address:** Make-A-Wish Foundation of New Jersey, 1347 Perrineville Road, Monroe Township, NJ 08831  
or jersey@wishnj.org

**Phone:** 800-252-WISH or 609-371-WISH

**Description:** No child should ever have to endure the struggle and pain that come with battling a life-threatening illness. Giving back to these children, what their illness has taken away – laughter, strength, hope and joy, is the sole purpose at the Make-A-Wish Foundation® of New Jersey.

According to their site “a wish begins once a child is referred to the Make-A-Wish organization. With the approval of the family, anyone can refer a child, whether it’s a parent, a teacher, a medical professional, a social worker, a friend or even the child. Upon receiving the referral, a confidential discussion with the child’s doctor is held to determine whether the child is medically eligible to receive a wish. Medical eligibility is based on the medical criteria established by the Make-A-Wish Foundation® of America and includes a broad range of life-threatening illnesses. Once medical eligibility is established, volunteers and staff take over from there. A volunteer team contacts the child’s family and sets-up an initial visit. The magic of a wish begins on that visit when their volunteers ask the child one simple question... The limitless answers, especially when fueled by a child’s imagination, are the very essence of what they do.”

These volunteers visit your home, sometimes with gifts for your children when they come to fill out paperwork. They will ask your child where he wants to go, what he wants to be, who he wants to meet, and what he wishes to have. They write down his favorite things to do and eat and his favorite actors and musicians. Your child will be asked to offer three wish ideas, along with timelines for granting them (especially for travel). You will be asked to sign releases and the like. Having a copy of your driver’s licenses will be helpful.

If your child is considering a wish at Disney World, you can consider staying at the Give Kids The World (GKTW) Village (<http://www.gktw.org/>). As shown in the wish step by step guide <http://www.gktw.org/wgo/pdf/wish-step-by-step.pdf>, your family receives on or off property accommodations, dining, character visits, activities, access to venues, and transportation. Additionally, with the support of Walt Disney World, GKTW has the ability to provide an amazing experience at all four of the beloved Walt Disney World parks: Magic Kingdom, EPCOT, Disney’s Hollywood Studios, and Disney’s Animal Kingdom. Each family member and the Wish Child receive three-day park hopper tickets, free of charge, as well as park hopper tickets to Universal Orlando (2 day) and SeaWorld Orlando (1 day). The Wish Child’s GKTW “Magic” button and a WDW Guest Assistance Pass provides “fast pass” service to the families, allowing them to fully enjoy the attractions offered at each park and cost-free parking! In their traditional style, Walt Disney World Cast Members provide excellent guest service to the families as well including an invitation to the Wish Lounge, located at the Magic Kingdom. This special room is dedicated to wish children and their families, recognizing the special needs and attention of each family.

Ideally, wishes should be granted within two years from the referral date to Make A Wish. Keep in mind that a child that has received a wish from another wish granting organization is not eligible for a wish from the Make-A-Wish Foundation®.

### **A Child's Wish Association of America**

**Website:** <http://www.childs-wish.org/>

**Address:** National Headquarters, 6623 Superior Ave, Ste B, Sarasota FL 34231

**Phone:** 800-617-9474

**Description:** Go to A Child's Wish Association of America's site to learn more about them. “[They were] founded to ease the pain and suffering of children who may be afflicted with a life threatening or terminal illness. For these unfortunate children [(ages 4 to 17)], A Child's Wish provides an experience of a lifetime in the form of a Special Wish.”

## ***Sibling Resources***

Following a diagnosis, it's easy to focus on getting your sick child well. These organizations help you provide the special attention that their siblings need as well.

### **Noogieland**

**Website:** <http://gildasclubsouthjersey.org/noogieland/> or

<http://www.gildasclubnyc.org/Membership/Noogieland.html>

**Address:** Gilda's Club South Jersey, 700 New Road, Linwood, NJ 08221 or Manhattan Clubhouse, 195 West Houston Street, New York, NY 10014, as well as other locations

**Contact Info:** 609-926-2699 or 212-647-9700 for the above places

**Description:** Part of what was formerly known as Gilda's Club; Noogieland is a place where children and teens (various ages) who have a loved one with cancer, have cancer themselves or have experienced a loss due to cancer can gather for support. Kids who have cancer in their lives often feel alone, confused and anxious. Research shows that kids who have cancer in their lives feel less isolated and fearful when they meet other children and families coping with a similar situation. Gilda's Club offers many opportunities for kids to meet other kids who have been affected by cancer too. Visit the website of the Club nearest you to see what programs are offered for what age groups, including siblings.

### **The Sibling Support Project**

**Website:** <http://www.siblingsupport.org/>

**Contact Info:** 206-297-6368 or [donmeyer@siblingsupport.org](mailto:donmeyer@siblingsupport.org)

**Description:** Visit <http://www.siblingsupport.org/> to honor your cancer warrior's siblings. There you will become aware of “the Sibling Support Project [which] is a national effort dedicated to the life-long concerns of brothers and sisters of people who have special health, developmental, or mental health concerns. [They] believe that disabilities, illness, and mental health issues affect the lives of *all* family members. Consequently, [they] want to increase the peer support and information opportunities for brothers and sisters of people with special needs and to increase parents' and providers' understanding of sibling issues.”

“[Their] mission is accomplished by training local service providers on how to create community-based peer support programs for young siblings; hosting workshops, listservs, and websites for young and adult siblings; and increasing parents' and providers' awareness of siblings' unique, lifelong, and ever-changing concerns through workshops, websites, and written materials.” Check out their site to register for workshops in your area or see a list of sibling-related books.

## **Supersibs**

**Website:** <http://www.supersibs.org/>

**Contact Info:** 888-417-4704 or info@supersibs.org

**Description:** As stated on their site, “Supersibs [is a national non-profit organization that provides] services to support and honor the brothers and sisters of children diagnosed with cancer. ... [They] are pleased to provide [their] mailed comfort and care services to siblings who live in the U.S. and Canada. These services are completely free of charge to sibs of children with cancer between the ages of 4-18, and are intended to bring moments of delight and support to these ‘shadow survivors’. [Their] website is available to support siblings and families around the world as well. [Their] education and outreach materials are provided to medical, education and psychosocial professionals directly in the U.S. and Canada, and also to others worldwide, via the internet, so each can support siblings on-site.” Refer siblings through their online referral form. None of the information you supply will be shared outside of the program.

## **Other Cancer Resources**

The following resources are not necessarily focused on childhood cancer patients or their families like the other resources we have already covered. However, someone we know found them helpful and they may be of use to you, or someone else you know with cancer.

### ***Assistance***

#### **Cleaning for a Reason:**

**Website:** <http://www.cleaningforareason.org/>

**Contact Info:** 877-337-3348

**Description:** If you know any woman 18 years or older currently undergoing chemotherapy, please direct her to this site. Cleaning for a Reason is a service that provides *free* housecleaning - once per month for four months while she is in treatment. All she has to do is sign up with their online registration and have her doctor fax a note confirming the treatment. Cleaning for a Reason will have a participating maid service in her zip code area arrange for the service. This non-profit organization serves the entire USA and currently has over 500 partners to help these women. There are people out there that care. Be a blessing to someone and pass this information along.

### ***Organizations***

These organizations are comprised of the people you will rely on throughout your child’s treatment for care: the nurses, social workers and child life specialists.

#### **Association of Pediatric Hematology Oncology Nurses**

**Website:** [www.aphon.org](http://www.aphon.org)

**Description:** Go to their site to learn more about this organization. “The Association of Pediatric Hematology Oncology Nurses (APHON) provides and promotes expert practice in pediatric hematologic/oncology nursing to its members and the public at large.”

**Association of Pediatric Oncology Social Workers**

**Website:** [www.aposw.org](http://www.aposw.org)

**Description:** "The Association of Pediatric Oncology Social Workers (APOSW) is a group of passionate, professional oncology social workers. [Stated on their site, their] efforts are focused on enhancing the lives of children with cancer and blood disorders and the families who care for them. [They] accomplish [their] mission by advancing pediatric psychosocial oncology care through clinical social work practice, research, advocacy, education, and program development."

**Child Life Council:**

**Website:** [www.childlife.org](http://www.childlife.org)

**Description:** Check out [www.childlife.org](http://www.childlife.org) to find out more about the Child Life Council. "Established as a non-profit organization in 1982, the Child Life Council represents a group of trained professionals with expertise in helping children and their families overcome life's most challenging events. The Child Life Council membership is composed of nearly 4,500 individuals representing more than 600 organizations worldwide. [Their] members include child life specialists, child life assistants, university educators and students, hospital administrators and staff, school teachers, therapeutic recreation specialists, and others in related fields. CLC provides members with professional development programs and resources, facilitates the exchange of professional knowledge and best practices, and distributes information about the needs of children experiencing stress and trauma."

## Appendix: Packing List for Hospital Stays

- Comfortable clothes and pajamas for you for a few days, including sports bras for sleeping, extra socks and a sweater
- Comfortable clothes and pajamas for a few days for your child
- Toiletries, including toothbrushes and toothpaste for you and your child
- Phone/iPad, with charger
- Child's medications from home in their original containers. The hospital pharmacy may scan them for hospital use. If you forget these, the pharmacy may give your child a different medicine than he/she is used to.
- Medications for yourself for longer than you plan to stay (i.e., headache or pain relief, birth control pills, blood pressure meds, etc.)
- Notepad and pens
- Laundry care, such as Purex Complete 3-in-1 Laundry Sheets or Tide Pods
- Novels, crossword or word search books
- Electronic toys and chargers for your child
- Instant coffee packs that have the cream and sugar already added
- Hair accessories
- Non-perishable food items and drinks to snack and supplement what's offered in the hospital
- Things that remind you and your child of home

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