XII. MEDICAL POLICY

General Statement

All camp volunteers are responsible for the safety and good physical care of all children who are entrusted to our care. The Medical Director and medical staff are especially responsible to ensure the physical well-being of our campers.

Among other things, the Medical Director will:

make an emergency first aid and emergency transportation plan for all camp activities;

provide appropriate first aid supplies for all camp activities;

educate staff in emergency care and reporting; and

review annually all current medical policies with each member of the medical staff.

The medical policies stated herein shall serve as minimal guidelines to all volunteers and must be strictly adhered to by all personnel, except in such circumstances as the Medical Director shall direct.

Philosophy of Operation

The camp health program operates under the direct supervision of the Medical Director, in accordance with guidelines provided by the Family Independence Agency, and the Children's Oncology Group's best practice guidelines. All campers, camp personnel, and others involved in the program are expected to abide by all policies, rules, and regulations implemented by this person.

The camp's health program is designed primarily to take care of the campers' normal daily needs (such as medication management, first aid needs, and health maintenance) and to refer to specialized medical personnel (such as hospitals) or parents/guardians any special or emergency needs that a camper might have. If a camper should develop a specific health problem that necessitates his or her removal from normal camp activity and requires special health care, whenever practical the camper should be returned to the care of the parent/guardian and return to camp once the problem is resolved.

General Method of Operation

A physician shall be on duty for the camp at all times – 24 hours a day. At least one registered nurse will be on duty at all times to deal with health maintenance as well as emergency issues.

Medications will be distributed at each meal and at bedtime and/or as needed.

A medical professional will remain in the medical facility whenever a camper is present in the facility.

The medical staff provides an information sheet on each camper to each cabin's Counselors to enable the counseling staff to properly oversee medication times and other patient conditions.

The medical staff develops a system for logging medications, treatments, and procedures performed on individual campers. A copy of this log, and any subsequent reports, is returned to each camper's parent or guardian if there are any unusual occurrences.

When information about a camper's physical, emotional, mental, or family situation is shared with necessary staff for the purpose of providing optimum medical and psychosocial support to the camper, it remains confidential.

Orientation to other camp staff on special care of children with cancer is provided to all camp staff.

The "Med Shed" will be housed in a suitable facility that provides protection from the elements, space for the treatment of injury and illness, a lockable medication storage system, an available toilet, and available water for drinking and cleaning. There will be at least one bed for every 50 campers and staff and a quiet private room that affords isolation, if necessary.

Health Information and Registration Form

The camp maintains a standard Health Information and Registration Form for all campers and staff, including a Physician Form signed by a physician or nurse practitioner. It is mandatory that a properly completed form be submitted, prior to camp, for each camper and staff member attending camp. The health history form includes any current health issues/needs, past medical history, allergy information, and names of the camper's health care providers. All emergency medical treatment consent forms for campers are copied in duplicate – one copy is retained by the Medical Director and the other by Camp Director. All health information forms will be stored for the time period required by Texas law.

Medications

The process of collecting medications from campers, caring for them, and dispensing them to campers shall remain the responsibility of the Medical Director and medical staff.

All medications shall be stored in a secure location, under lock and key at all times.

Medications will be dispensed to campers in accordance with directions supplied by the camper's parent or guardian and prescribed by the camper's physician.

No prescription medication will be administered to a camper unless the prescription is in the camper's name. Prescription medication under the parent's name will not be administered to the camper. All medications need to be brought to camp in the original container.

Campers often bring a variety of minor medications to camp including cough drops, non-prescribed cold remedies, ointments, vitamins, etc. These items shall also be collected by the nurses from the campers and deposited in the medical facility. They shall be dispensed by the medical staff as per parental and/or physician's instructions.

Medications may only be distributed by licensed medical personnel.

Medications for staff/volunteers must be kept in a secure location inaccessible by campers.

Minor Illness

Minor illness is defined as those simple minor ailments that are commonly incurred by children. Examples include upset stomach, nausea, colds, sore throat, headache, earache, homesickness, fatigue, etc.

Children suffering from minor ailments should be reported directly to the staff member who is immediately responsible for their supervision. This staff person shall then refer the problem to the medical personnel.

At the medical personnel's discretion, the child may be removed temporarily from normal activity and placed in the "Med Shed" under the nurse's care.

A child with a temperature of 100º F or more will be isolated as much as possible from contact with other children for a reasonable time. If there is apparent illness after that time, isolation will continue and the option of returning the child home will be considered. If a temperature of 100º F or greater occurs in a child with likely neutropenia or who has received myelosuppressive chemotherapy in the past 30 days, CBC-platelet will be obtained and the child will be seen by medical staff immediately. Handling the problem will be referred to the guidelines of the Serious Illness Policy.

If, after a reasonable time, the symptoms of the ailment are not alleviated, the Medical Director and or his or her designee shall notify the child's parent or guardian.

Accidents and Sudden Serious Illness

The physician and/or nurses may care for minor injuries.

Minor injuries may be defined as those that cause little physical damage and require little care. Examples include small cuts, bumps, bruises, particles in the eye, etc.

In the event a camper becomes a victim of a more serious accident or sudden serious illness, the following procedure will be followed:

The Medical Director, physician, and/or nurse shall be immediately notified.

An immediate attempt will be made to determine the nature and extent of the child's illness or injury and appropriate emergency protocol instituted.
The Medical Director or his or her designee shall immediately attempt to notify the child's parent or guardian. The child's parent or guardian shall make a final decision on the course of action with medical staff.

In case of a serious accident or illness where it becomes necessary to secure immediate hospital treatment, the child appropriately will be transported to the hospital.

The Medical Director or his or her designee will attempt to contact the child's attending physician to mutually arrive at a plan to best handle the illness or injury. Such contact will occur as soon as the circumstances of the illness can be clarified. If contact cannot be made in a reasonable time, the camp physician or Medical Director will make necessary care arrangements after discussion with a parent(s) or guardian.

Emergency first aid may be given to a camper who is the victim of an accident or sudden illness by any staff member or other adult who is qualified to render such service until which time the physician or the nurse comes in contact with the camper.

Arrangements for On-Call Health Consultation and Emergency Care Services

Arrangements shall be made prior to camp with a local Pediatric Oncology Program for routine services (laboratory) or Emergency Medical Services (Emergency care, pediatric and adult inpatient care, diagnostic radiology, and laboratory services). A copy of every camper's Health Information Forms will be kept on hand at all times, including off-site activities, in the event they are needed to deliver appropriate health care.

Medical Procedures for Trips Away From Camp

Procedures for medical emergencies will be in written form and reviewed by the nurse with each staff member responsible for carrying them out. A copy of each camper's medical history form and parent authorization form will accompany any camper on trips away from the main camp. The Medical Director will establish procedures for dispensing medications while the camper is away from the main campsite. A medical staff member will accompany any group with activities away from the campsite which is out of radio contact of the main camp. If access to EMS is 20 minutes or less, a person will have nationally accredited first aid and CPR training. If EMS services are 20 minutes away, a registered nurse or licensed physician, or nurse practitioner will accompany the group.

XIII. COMMON MEDICAL/PSYCHOSOCIAL INFORMATION FOR ALL STAFF

Psychosocial Aspects

**** Developments In The Field Of Pediatric Oncology***

Two developments in the field of pediatric oncology over the last twenty years have led to the feasibility and desirability of special camps. It has become medically possible to both establish and maintain stable remission patterns and to permanently cure many patients. As a consequence of these increasing survival rates, the psychosocial and developmental needs of young cancer patients are being given much greater attention. Camps are able to meet some of these needs very effectively.

**** The Non-Medical Side Of Cancer***

The shift in focus from medical cure alone, to both cure and psychosocial rehabilitation, reflects the natural progression of a successful treatment program. A child who is newly diagnosed is suddenly thrown into a strange new adult world where the cure may seem worse than the disease itself. Family life may be dramatically disrupted as all of the family relationships are suddenly redefined. The child may fall behind in school and be a victim of the social stigma of cancer, schoolmates may make fun of a child's physical appearance, they may make uninformed remarks, or ask a lot of disturbing questions ("When are you going to die?"). There may be a fearful preoccupation with thoughts of death, suffering, and relapse. Psychological transformations brought by the disease and treatment process may reduce the effectiveness of future treatments. Being different isolates one from one's peers, significant others, and even one's former self. Thus, when considering a total cure, the medical community cannot overlook the damage that cancer's fallout inflicts on a child's mind and spirit. Our mission is to help these kids see themselves as normal kids again or kids that can do normal things.

**** Normal Treatment***

Given the often-traumatic demands of living with cancer, it appears best to view these children as normal with special needs. Kids with cancer don't want to be treated differently; yet, at the same time, some will want you to have a sense of the hard times they had or are having, without feeling sorry for them. There are also children who should properly be seen as special kids with special needs. Some children who are dying, and for whom normal childhood development is impossible, may fall into this category. On a practical level, the few children you will encounter who fit into this last category are likely to define their own needs, and these will likely be that you treat them like everyone else.

**** Ability To Handle Special Needs***

Children with cancer have been denied access to regular camps because of fear or ignorance of the camp staff, the campers' disabilities, specific medical needs that could not be met, or the

increased risk of infection. Cancer is still the number one disease threat to a child's life, and we believe we have a responsibility to help if we can. For some children, anticipation or the possibility of death may play a real role in the struggle to survive and live well.

Bringing children together who have shared similar life experiences can generate both negative and positive results. For the most part, the experiences are positive: the children are quite sensitive to each other's feelings, are less likely to make hurtful fun of one another, and come quickly to each other's aid. It is imperative that the staff, volunteers, and counselors be sensitive and aware of the different issues that arise. Staff and volunteers who do not have professional medical or psychosocial training should not initiate discussions about cancer-related matters, nor should they offer directive advice. They are friends that can offer a sympathetic ear and deal with the usual worries of campers but are also advised that a camper's apparently innocuous remarks and concerns may reflect a more serious problem. For this reason, staff and volunteers should be aware of who they can go to for assistance and keep the lines of communication open.

Medical Information for All Staff

The Camp Atmosphere

Camp is not to be seen as a place for dying children. Compassion and understanding are appropriate responses to these children whose lives have been disrupted, but not pity. It is simply defeatist and counterproductive to ground camp in a "last chance for fun" philosophy. This does not mean we should lose sight of the fact that some children will not be coming back, but this realization should provide the motivation for that extra effort it takes to risk sharing ourselves and to really work at making the program a success.

Sun Protection

Many campers are very sensitive to the sun because of the drug and radiation therapies they are getting. Even those who are not sensitive should wear sunscreen to reduce their risk of skin cancer. Apply and re-apply sunscreen liberally to the campers and to yourself. The medical staff has sunscreen if the campers do not.

Bug Bites & Rashes

Report all bug bites and rashes to the medical staff.

Allergic Reactions

Know your campers' allergies. Campers may have allergies to food (nuts, shellfish), drugs (penicillin, codeine), or insects (bees, wasps). Think: Grub, Drugs & Bugs!

Scrapes & Twists

Report any twists and scrapes to the medical staff.

Signs to Watch For: Report to the medical staff any of the following symptoms:

– Fever
– Bleeding that cannot be stopped
– Bruising easily (especially if the camper is known to have low platelets)
– Unusual pain, including headache
– Shortness of breath
– Reports of blood in urine
– Excessive thirst or vomiting
– Reports of diarrhea
– Sores or ulcers in the mouth or on the skin
– Jaundice (yellow tint to skin or eyes)
– Rash, swollen hands or feet (signs of allergic reactions)
– Problems with eyesight
– Persistent headaches
– Decreased or poor appetite

Best Rule of Thumb – When in Doubt Report All Observations to the Medical Staff.

Children With Cancer

General Overview and Survival Rates

Cancer is actually a group of diseases, each with its own name, its own treatment, and its own chances for control or cure. It occurs when abnormal cells begin to multiply and grow uncontrollably, crowding out the normal cells. As yet, we do not fully understand why normal cells mature and cancerous cells do not, the latter resulting in the local accumulation and spread of tumors.

Today, a young person with cancer stands a good chance of surviving the disease. From 1951 to 1991, the long-term survival of childhood cancer has increased greatly. Advances in all types of treatment including surgery, radiation therapy, and chemotherapy (anticancer drug therapy), including the use of more intensive treatment regimens, have produced this dramatic increase in survival.

Types of Childhood Cancer

The types of cancer seen most commonly in children differ from those in adults. Leukemias (cancers of the blood-producing tissues), lymphomas (cancers of the lymphatic system), and brain tumors are the most common pediatric cancers. Solid tumors (*i.e.*, bone) affecting other parts of the body such as arms or legs, and muscle tumors (Rhabdomyosarcoma) can be seen in any muscle in the body. Wilms Tumor is a kidney tumor. Cancers in children are more successfully treated than cancers in adults. They tend to grow more quickly and are, therefore, more susceptible to chemotherapy and radiation.

The Leukemias

Leukemia is cancer of the blood-forming organs, including the bone marrow, the spleen, and the lymph nodes. When leukemia strikes, the body starts producing a vast number of immature cells that do not mature or perform their proper functions. They also interfere with the manufacture of the correct proportion of red cells, white cells, and platelets.

The type of leukemia depends on the type of cell involved. The two major types are *acute lymphocytic leukemia* (ALL) and *acute non-lymphocytic leukemia* (ANLL), which is often used to classify the other less common types of acute leukemia such as *acute myelocytic leukemia* (AML), *acute monomyelocytic leukemia* (AMML), *acute monocytic leukemia* (AMOL), and *acute erythrocytic leukemia* (AEL).

ALL: In 80% of childhood leukemia, lymphocyte production goes haywire, leading to the form of leukemia called acute lymphocytic or lymphoblastic leukemia (ALL). The lymphoblasts (or blasts) stay immature, reproducing when they should not and crowding the bone marrow so that normal cells do not have enough room to multiply and mature. Eighty percent of all cases are seen in children, with more boys than girls affected. The incidence peaks in late infancy, preschool years, and around puberty. Forty percent of cases occur in children between the ages of 3 and 5.

ANLL: This accounts for nearly 20% of leukemia in children. Unlike ALL, there is no age at which ANLL peaks in children. Its incidence increases with age, from childhood through adolescence and young adulthood to middle age, dropping after age 65.

The Lymphomas

Lymphomas, which usually originate within lymphoid tissue, is the second most common malignancy in the young. There are two broad types of lymphoma, Hodgkin's disease, and non-Hodgkin's Lymphoma. Both are characterized by abnormal masses in the lymph system.

The lymphatic system is a network of nodes and tiny tubes or vessels that drain fluid from spaces in the body's tissues. The lymphatic system destroys foreign matter and produces antibodies to fight infection. Lymph nodes are found in the armpits, groin, neck, mid-chest, and abdomen.

Non-Hodgkin's Lymphoma: In children, non-Hodgkin's lymphoma can arise in the tonsils, thymus, bone, small intestine, or spleen or in lymph glands anywhere in the body. The disease can spread to the central nervous system and the bone marrow. This lymphoma is more common in children than Hodgkin's disease. Boys are generally more affected than girls. The age of onset is about 5 to the teens with a peak between 7 and 11. The disease is rare before the age of 3.

Hodgkin's Disease: Hodgkin's disease is the most common form of lymphoma in adults. This disease tends to affect the peripheral lymph nodes like those in the neck, rather than those in the trunk. Half of the patients are under age 25 at the time of diagnosis. This malignancy reportedly peaks in boys before puberty and in girls in late adolescence.

Brain and other Central Nervous System Tumors (CNS)

Tumors of the brain and spinal cord are the most common type of primary solid tumors in children. Leukemia is the only malignancy more common in young patients. There has been less dramatic progress in treating these tumors because they are hard to diagnose and treat. Improvements in neurosurgery techniques and radiation therapy have increased survival so that the diagnosis of a brain tumor is no longer the end of hope. About 20% of all primary brain tumors arise in children under the age of 15, somewhat more in boys than girls. There is a peak between the ages of 5 and 10. Radiation therapy to treat brain/CNS tumors may cause learning disabilities and developmental delays in some children.

Spinal Cord Tumors: Spinal cord tumors are relatively rare in children, accounting for less than 5% of all CNS tumors. When they do occur, they are usually metastases (cancers that have spread) from primary tumors located elsewhere.

The Sarcomas

Bone cancer is one of the more common types of malignancy found in young people. Most tumors in the bone are metastases from cancers arising elsewhere in the body, although some tumors do originate in the bone. The two main types of primary childhood bone cancer are *osteogenic sarcoma* (most common) and *Ewing's sarcoma*.

Bone and connective tissue tumors account for only about 1% of all human cancers, but in the 10-20 year age group, they are the fourth most common cancers. Two-thirds of all cases are seen in patients under the age of 20. These tumors seldom appear before the age of 4 and peak in early adolescence. There is some suspicion the growth of bone sarcomas is related to bone growth.

Soft Tissue Sarcomas: Soft tissue sarcomas are malignant tumors arising from the muscle, connective tissue, blood vessel, and fat.

Rhabdomyosarcoma: Rhabdomyosarcoma is a muscle tumor. It is the most common soft tissue sarcoma in children. The occurrence peaks between 2 to 6 years of age and again between 15 to 19. Ten percent of cases appear before age 1 and 70% appear in the first 10 years of life. It can occur in any muscle tissue in the body. The most common sites are the head and neck (including the eye

socket) and the genitourinary tract. Primary tumors are also found in the muscles of the limbs, buttocks, and trunk.

Synovial Sarcoma: Synovial sarcoma is a cancer, that most frequently affects young adults and is found only rarely in children. The average age of the children affected is between the ages of 10 and 14. The main symptom is a firm, relatively slow-growing mass that is only occasionally accompanied by pain. Most all synovial sarcomas are located in the extremities, especially the ankle, foot, hand or knee. They appear less often in the chest wall, groin, skull or neck.

Neuroblastoma: Neuroblastoma attacks the nervous system. It is a highly malignant growth that spreads quickly. The nervous system is the network of organs and tissues that control and coordinates all of the body's activities. Though neuroblastoma is a commonly seen childhood cancer, its incidence in the general population is relatively low. Affected children are very young with one-third of the diagnoses occurring in the first year of life and one-half in children under the age of two. Only very rarely is it seen in children over the age of four. Males are affected slightly more than females. The disease can rise in nerve cells anywhere in the body, but the primary tumor sites are the abdomen or pelvis. Other sites are the chest, neck, and within the skull mostly beginning with the adrenal gland.

Wilms Tumor: Wilms Tumor is a rare malignant solid tumor of the kidney usually found in children between 1 and 5 years old. It is considered a congenital disorder regardless of the child's age at diagnosis since it arises from embryonic tissue (fetal cells that develop early in pregnancy). This form of childhood cancer peaks at ages 3 to 4 with 90% of cases diagnosed by the age of 8. There is a clear link between a genetic defect in chromosome 11, which produces the colored part of the eye, and the subsequent development of Wilms Tumor.

Retinoblastoma: Retinoblastoma is a highly malignant cancer of the retina of the eye. It accounts for 2% of childhood malignancies. This tumor grows rapidly and if untreated, spreads elsewhere in the body. Some forms of retinoblastoma are known to be inherited, and a clear genetic link has been discovered. Retinoblastoma is the only childhood cancer with enough survivors over enough generations to study the hereditary patterns. Siblings of retinoblastoma patients have a risk of developing the disease, as one of the parents could be a carrier. The incidence of retinoblastoma is increasing because improved treatment methods have increased the number of survivors who then pass the disease to their children. Most are discovered before the age of 2 with an average age of 18 months. It is rarely found after the age of 5.

Effects of the Disease and Treatment

The goal of treatment is to remove or destroy the abnormal cells by surgery, radiation or chemotherapy, or some combination of these methods. Initial treatment may be

intense and then may become more moderate depending upon the young person's response. It may be necessary to continue some form of treatment for many years.

Remission and relapse (or recurrence) are terms used to describe different phases of the disease. Remission is present when no detectable evidence of cancer is found. Relapse refers to the return of the disease after apparent improvement or a period of remission. Following relapse, the young person again undergoes treatment in an attempt to bring about remission. If a complete remission continues for a number of years (usually 2 to 10), the patient's doctor may begin to consider the person "cured."

Both the disease and treatment can produce physical changes in the patient such as nausea, vomiting, and fatigue, which decrease energy levels and the ability to participate in school or other activities. Other possible changes, which are usually temporary, include weight gain or loss, mood swings, facial fullness and distortion, problems with coordination, difficulties with fine and gross motor control, body marks resembling tattoos (to identify sites for radiation therapy), and muscle weakness. Patients with solid tumors may have surgical changes such as scars or amputation.

Hair loss occurs in many patients undergoing chemotherapy and may be the most disturbing aspect of their treatment. The hair may fall out suddenly or over a period of weeks or months. It may grow back while the patient is still receiving therapy, but doesn't usually return to normal until after treatment is completed. The young person will often wear a wig, hat or scarf to hide the loss. Any of these physical changes can result in fear of or actual teasing and rejection by peers. This can create a reluctance to resume friendships and to return to school. When it does grow back, hair may have a different color or texture (*i.e.*, curly or straight) than before.

Young people with cancer also must face emotional challenges. They fear relapse and the subsequent repetition of treatments. Emotional energy usually spent mastering basic developmental skills now is used to cope with the illness. For example, teenagers have difficulty attaining the independence so important to their development when the disease forces them to be dependent on parents and caregivers. In addition, the young person must learn to deal with others who treat them differently because of their disease and may subsequently seem to withdraw, regress, or become belligerent.

Despite the outcome of the disease, it is important to pay attention to the quality of the young person's life. Although they have a serious illness, they are still growing and developing and have the same educational and social needs as their peers.

The Treatments: Surgery, Radiation, and Chemotherapy

Care of a child with cancer goes beyond prescribing surgery, radiotherapy, or chemotherapy. It includes measures to prevent or lessen any pain or discomfort which is associated with the disease or its treatment and anticipation and management of the side effects of the treatment.

Once the child's disease has been diagnosed and the extent or stage is known, the treatment team gets together to decide who will do what and when. The theory of modern management of cancer is very basic:

- The surgeon removes the tumor or biopsies the tumor (depending on the tumor type), if possible (applies only to solid tumors or lymphomas, not leukemia).

- Radiation therapy to clean up remaining cancer cells in the area where the tumor was found; radiation therapy may be localized or given to the entire body.

- Chemotherapy with antineoplastic medications may be given to kill off even invisible clumps of cells that have migrated elsewhere.

Each of these types of treatment may be given alone or in a combination with one or both of the others. This depends on the type of tumor, its location, stage, and numerous other factors like the child's general state of health and age.

Nausea and vomiting are frequent treatment side effects, which have been lessened by the introduction of more effective anti-emetics (anti-nausea drugs). Less invasive local anesthetics, such as topical creams, rather than needles, have reduced the pain of many tests and procedures. Anti-anxiety medications and sedatives ease the anticipatory anxiety and pain frequently experienced with procedures such as bone marrow aspirations and spinal taps. The use of central lines and port-a-caths has reduced the number of needle punctures young patients must endure for blood sampling and intravenous treatment.

The treatment of cancer in children and teens is complex and requires a multi-disciplinary approach. Physicians, nurses, therapists (occupational, physical, and respiratory), technicians, dietitians, pharmacists, child life workers, social workers, psychologists, teachers, volunteers, and personal counselors work to maximize a young patient's physical and emotional well-being.

Surgery

Surgery is the oldest and still most widely used treatment for cancer patients with solid tumors. Removing the primary tumor sometimes makes even widespread cancer treatable by chemotherapy. Still, surgery plays its most important role in the early stages of the disease, when a great percentage of patients can be successfully treated. Unfortunately, not all tumors are operable, depending on their size and site.

Radiation

About one-half of all children with cancer receive radiation therapy. It is most often used in the early stages of the disease when the cancer is still localized, but too advanced for a surgical cure. After the primary tumor has been removed, radiation effectively cleans up tumor cells that may have been left behind. It

combines neatly with surgery for it "gets" the residual local cells that the operation misses, while surgery can handle a large tumor that radiation could not cure. Some tumors that do not require surgery may be cured by radiation alone.

Radiation therapy destroys the cells by eliminating their ability to divide or to mature. All tissues and tumors are susceptible to radiation to some extent. It may vary from tumor to tumor within the same type and even within the same mass at different moments.

There are clear benefits in treating a child with radiation. Radiation therapy doesn't hurt, individual treatments are not time-consuming (although they may be given daily for weeks or months), and they may salvage body functions that surgery would destroy. They usually require little or no hospitalization and, unlike surgery, there is no risk of spreading the tumor during the treatments.

On the other hand, radiation is not without disadvantages. Normal cells will be damaged. In small children and infants, the growth patterns of bones and other tissues can be altered. There is the possibility that a second cancer may appear some years later. If the pelvic area is radiated, sterility may result. These risks have to be weighed against the benefits when therapy is planned. New equipment has reduced some of the side effects and enhanced the effectiveness of the radiation. Radiation therapy of tumors has increased the survival rates of patients by leaps and bounds.

Radiation to the brain and spinal cord may be used as a preventive measure for certain patients who have evidence of leukemia in those areas at the time of diagnosis. Total body radiation is also used sometimes to "turnoff" the patient's own immune system and to eradicate all traces of leukemia or other cancer before a bone marrow transplant.

The dosage and timing of the treatments are critical. It takes expertise to calculate the exact doses that will control the tumor without causing overwhelming future problems. If chemotherapy will be part of the regimen, it may be necessary to alter the dose because some drugs enhance the effects, good and bad, of the radiation. The doctor who plans the timing and length, site, aim, and dose of the radiation treatments is called a radiation oncologist or radiotherapist. External beam or teletherapy, projects radiation to the tumor site from a machine in a carefully targeted stream. Therapy is usually given on a daily basis, perhaps five times a week, over several weeks until the total dose is delivered.

Some of the early side effects of radiation therapy are:

– Hair loss (only in the radiation target zone)
– Depressed bone marrow and blood counts

- Nausea and vomiting (especially if the head or abdomen is in the target area)
- Diarrhea, constipation
- Fatigue which may be accompanied by dizziness, irritability, a decrease in appetite, vision problems, and temperature (if the nervous system has been radiated)
- Ear infection, dizziness
- Sore throat and sore or dry mouth
- Headache
- Skin burns

Late effects may not appear for some time; maybe years after the treatments have ended. These include:

- Alteration of growth patterns, especially in the very youngest patients
- Damage to the pituitary gland if radiated, which can lead to short stature
- Cataracts and inflammation of the eye covering and possibly suppression of tears
- Joint stiffness and impaired function if the joint is in the treatment field
- Injury to bladder, bones, kidneys
- Sterility (radiation to the pelvis)
- Bone fragility
- Tooth cavities
- Kidney damage in a single remaining organ
- Smaller breast growth and problems breast-feeding if chest is radiated
- Heart inflammation
- Delay of appearance of teeth
- Second malignancies
- Learning disabilities or developmental delays if the brain is radiated

This list looks pretty overwhelming, but remember that no child will experience all or most of these side effects. Additionally, the child may have little or no chance of survival if the therapy is not given, therefore the risks may be considered acceptable.

Chemotherapy

Chemotherapy, or chemo, is the treatment of cancer with drugs. It has brought about a revolution in the fight against cancer, particularly in children. Because drugs are distributed throughout the body, chemotherapy is used for leukemia and lymphoma, if they are known to be widespread at diagnosis. Also, chemotherapy is used for solid tumors that are assumed to have spread at the time of diagnosis. By the time most tumors are discovered, there is a good likelihood that at least a few of those cells are elsewhere in the body, having

been carried away from the tumor by the bloodstream or in the lymph system. Using chemo to find and destroy these cells is called adjuvant or adjunctive chemotherapy.

Currently, doctors use many drugs that kill cancer cells. Doctors hope that chemotherapy drugs will help their patients by seeking out and destroying tumor cells hiding throughout the body. These treatments are the best hope for children with most forms of widely metastasized cancers.

Most chemotherapy drugs cause a temporary lowering of the blood cell counts. When these counts are low, children and teenagers with cancer have an increased chance of getting an infection. They have more difficulty fighting certain infections and may bleed more easily. They may require transfusions with red blood cells or platelets. A child or teenager who develops a fever or major infection may be admitted to the hospital for intravenous antibiotic therapy.

Episodes of infection can interfere with the scheduling of treatments. Children and teenagers treated with chemotherapy may be given an antibiotic to prevent infections. This is called antimicrobial prophylaxis.

Cancer cells can become resistant to individual drugs. Specialists use several drugs at the same time early in the treatment. Drug combinations are used to take advantage of agents that have different methods of action or that work on different schedules.

The drugs are often given over a series of daily visits followed by a few days or weeks of rest. Each series of doses is called a course. The team of specialists, through blood tests and physical examinations, carefully monitors chemo treatments. The major early side effect of most of the individual drugs and combinations is to lower the white blood count, the chief cells that fight infection. The count is checked before giving medications. If it drops so low that there is a danger of serious infection, there may be a pause in therapy while the body recuperates. Because many of the drugs are either activated or eliminated from the body by the kidneys or the liver, doctors also watch the functions of these organs carefully.

Central Line: Broviacs and Ports

Most chemotherapy patients receive a lot of their medication by intravenous injection. This can be a real problem, not only because the drugs are so potent and potentially dangerous but also because young patients have tiny veins.

Drawing blood and starting IV's to administer chemo is painful and stressful for the child as well as the rest of the team. Now many patients can avoid these ordeals by having a "central venous access line" or "central line." A central line is a permanent intravenous tube or catheter, which can stay in place as long as it is needed. There are

two main types of central lines. One type is entirely under the skin (an "internal line") called a Port-a-cath. The other has tubing outside the skin (an "external" line) called the Broviac or Hickman, or PICC line. Both have a long thin tube that reaches the large vein that goes close to the heart. Internal lines cannot be seen once they are under the skin. The internal line is placed in the upper part of the child's chest by a surgeon in the operating room while the child is under general anesthesia. In order to use the internal line, a needle is put through the child's skin into a reservoir.

To prevent infection during the use of the internal line, the skin over it will be washed with an antiseptic soap. A substance injected into the port to keep blood clots from blocking it is called heparin. External central lines have tubing outside the skin (usually on the child's chest). To use this type of line, a needle is placed through the end of the tubing. This is not painful and it too must be flushed regularly to prevent blood clots. Because of the increased risk of infection among most chemotherapy patients, care of the catheter is especially important to avoid this major complication that may necessitate the removal of the device.

It is very important that the external central line site be kept clean and dry. Children and teens with an external Broviac must have the permission of the medical staff before they are allowed to go into the swimming pool. If these children are allowed to swim, the external dressing MUST be changed immediately after the end of the swimming period. Campers may have their Broviac dressing pinned to their shirts and care should be taken that their clothes are not pulled on or off.

Communicable Diseases and Chicken Pox

Infection is serious for children on treatment, and it is the leading cause of serious complications and death. Cancer patients have a significantly higher risk of contracting communicable diseases like colds and childhood illnesses like chicken pox. Chickenpox is considered a medical emergency since it can become a very serious illness when contracted by a patient on chemotherapy. The complications may easily become life-threatening. If you have not had chickenpox and plan to attend camp, you MUST ensure you are not exposed to chicken pox or shingles for at least one month before attending camp. This does not apply if you have received two vaccinations for chicken pox after chicken (also called the VZV vaccine).

Once a child or teen has been exposed to chicken pox they must be isolated for 28 days. Chickenpox will appear as red spots with blisters. Children are infectious 1-2 days prior to developing the rash until all the lesions are crusted over. Shingles are caused by the same virus that causes chickenpox; however, only those who have had chickenpox can get shingles. You cannot get shingles from others, although those who have not had chickenpox can develop it from coming in contact with shingles.

While infections are generally caused by bacteria, viruses, and fungi, it is difficult to isolate the campers in the camping environment. Therefore, the most important way to fight off unwanted bugs is hand washing, not just for the child in therapy, but for everyone!

Blood Counts

While Blood Cell (WBC) Counts

Description: White blood cells are an important part of the body's defense system, and they respond immediately to foreign invaders, going to the site of involvement. High white blood cells may indicate a poorly functioning immune system. High white counts may also indicate an infection. Low WBC means the patient is at increased risk for infection.

Implications: If a low WBC is present, ensure that the child is protected from chicken pox and the germs associated with a "common" cold. A low WBC makes the child prone to infections which can be life-threatening to the child with cancer. If high WBC is present, watch the child for signs of infection or inflammation (*i.e.*, high temperature, fatigue, and increased pulse and respiration rate). Report these observations to the medical staff immediately.

Hemoglobin (Hgb)

Description: Hemoglobin is a protein substance found in red blood cells. Hemoglobin is composed of iron, which is an oxygen carrier. Abnormally high hemoglobin levels may be seen as a result of hemoconcentration. This may be caused by dehydration. Low hemoglobin values are related to various clinical problems (*i.e.*, anemia, iron deficiency, severe hemorrhage, chemotherapy treatment, and leukemia).

Implications: Low Hgb – watch for signs and symptoms of anemia (*i.e.*, dizziness, increased pulse, weakness, and difficulties breathing at rest). Report immediately. High Hgb – watch for dehydration (marked thirst, poor skin color, dry mucous membranes, and shock-like symptoms). Always make sure that the children and fellow campers alike have plenty of fluids.

Platelets (Plt)

Description: Platelets are needed for blood clotting. Thrombocytopenia (low platelets) is commonly associated with leukemia. Platelet counts may be decreased if a child is being treated with chemotherapy. Low platelets can cause bleeding.

Implications: Low Plt – watch the child for signs and symptoms of bleeding (*i.e.*, from gums, bruising on the skin, or rectal or urinary bleeding). Encourage the child to avoid contact sports and rough play and to avoid injury, as this may cause bleeding. In the event of an injury (*i.e.*, open wound) apply pressure to the site with a clean cloth and contact the medical staff immediately. Any other obvious signs of bleeding must be reported to medical staff.

E. Siblings Of Children Living With Cancer

Camp Peach Pals is proud to offer all the children touched by the cancer diagnosis, including the siblings of children living with cancer. There are many reasons why siblings are an important part of our camp family, just a few are listed below:

1. SIBLINGS of Pediatric Oncology Patients:

a) Miss as much school, but for different reasons
b) Bounce around between family and neighbors
c) Feel very acutely that the world has turned it's back on them. They feel they have become invisible
d) Internalize that they've done something wrong
e) Show a significant increase in the percentage of anxiety, depression, and suicide
f) Look to make a connection, a feeling they belong and are being paid attention to and these connections can be Negative or Positive.
g) Negative/Destructive: Gangs, Anti-Social Behaviors, & Drugs
h) Positive: CAMP

1. The camp experience can give siblings a sense that they are important, worthy and validate that they are normal and so are their feelings, they're just in an "unfortunate situation".
2. The camp experience can help lead siblings onto a Post Traumatic Growth Trek not Post Traumatic Stress Disorder
3. The camp experience has helped siblings recognize their ability to help and these siblings have become true leaders in the field of giving and taking care of others (like they have been doing for their sick sibling)
4. The camp offers the opportunity for social networking with those that share a common ground, a community where you can feel safe and supported. Siblings need a camp too.

The following information can be found at: https://www.cancer.net/blog/2017-05/how-help-healthy-children-cope-when-sibling-has-cancer

2. How to Help Healthy Children Cope When a Sibling Has Cancer

When a child is diagnosed with cancer, family dynamics will change. Those changes can be extra hard for their siblings. Understanding their viewpoint—and all of the emotions and behaviors that go with it—makes it easier to meet their needs.

And while there may be challenges, at the same time, many children respond to a sibling with cancer with enormous love, care, and support. Parents often see other, positive changes in siblings of a child with cancer, including more empathy and compassion, greater self-esteem, closer relationships with siblings and parents, and greater insight into the things that really matter.

3. These are 3 tips to help you with understanding our Sibling Campers:

1. Recognize emotions that siblings may feel

Brothers and sisters of a child with cancer experience *a lot* of emotions, many of which are similar to those felt by you and other adults. Age and coping skills affect how a sibling may react. Here are some common feelings:

a. **Fear and anxiety.** Younger children may fear they caused the cancer somehow or that they might "catch" it. Others worry about what will happen to the family because of the cancer. Or, they may fear that their brother or sister may die.
b. **Anger, jealousy, and resentment.** Healthy siblings can be angry with their parents for not having as much time for them. They may be angry at the child with cancer for this, too. Siblings may resent that the child doesn't have to do chores or go to school.
c. **Feeling alone.** Healthy siblings may feel left out, especially if most activities as a family involve the hospital and doctors' visits. Or, siblings may feel that they've lost the friendship of the child with cancer. Siblings may also miss time with friends if you can't take them to regular social outings due to the demands of a child's cancer treatment.
d. **Guilt.** Often, healthy siblings feel guilty for not being the sick child. They may feel guilty for having bad thoughts or saying mean things to the child or for having any of the common emotions mentioned above.
e. **Sadness and grief.** Siblings may feel sad for the child with cancer and for their parents. They may feel sad that everything seems to have changed and grieve the loss of a "normal" family life.

2. Understand what behavior to expect from siblings

Children often don't know how to talk about their feelings, so they express them through actions. Every child is different, but common and normal responses from healthy siblings can include:

a. Misbehaving or acting out in negative, attention-seeking ways at home or school
b. Increased anxiety, such as not wanting to leave their parents or to go to school
c. Withdrawing from the family or wanting to be alone
d. Acting younger, such as a preschooler wanting to go back to diapers or an older child using baby language
e. Demanding or entitled behaviors, such as wanting a new toy during every trip to the store
f. Having physical symptoms, such as headaches, stomachaches, or bedwetting
g. Having trouble sleeping and/or bad dreams
h. Being moody and irritable, including temper tantrums, fighting with parents or siblings, or crying a lot
i. Performing worse in school or having a hard time focusing on homework
j. Doing "extra good" deeds to try to take care of the rest of the family

3. Help siblings cope

There's no way to "fix" every fear or feeling. But now that you know the emotions and behaviors to look for, you can help your children cope with the stress and emotions that a cancer diagnosis brings. Here's how:

a. **Be open about cancer.** Give healthy siblings age-specific, honest information. Explain that cancer can't spread to other people and that doctors are doing all they can to help their brother or sister get better. Encourage questions and provide frequent updates, which can help siblings feel less anxious when they have to answer questions from teachers and friends.
b. **Reassure them that they're equally loved.** Remind them that if they were sick, you'd be just as focused on helping them get better. Explain that your child's cancer is nobody's fault. Let them know how happy you are that they're healthy.
c. **Acknowledge feelings and worries.** Reassure them that their feelings—whatever they may be—are normal and okay. Help them express themselves through writing in a journal, artwork, or play. Tell them that you also feel sad, scared, and even angry, and explain how you cope.
d. **Spend time with them.** When possible, at least 1 parent should spend some time with the healthy children every day. "Family time" isn't about a big event or outing. It can be simply preparing a meal or watching a favorite show together. If you can't be there physically, talk on the phone or have a video call. Ask about their day and activities that are important to them. Tell them how much you miss them when you can't be there.
e. **Let them make decisions.** Try to let siblings make choices about things that affect them.
f. **Encourage them to do things they enjoy.** Tell them it's still okay for them to have fun.