



4720 Salisbury Road Jacksonville, FL 32256 • (904) 396-4223 • [childcancerfund.org](http://childcancerfund.org)

Dear family and friends,

The Child Cancer Fund is a unique organization started in 1994 by parents of children diagnosed with childhood cancer. Our mission is to support the entire family through our programs and services including a Child Life Specialist Position at Nemours Children's Specialty Care, Oncology Department, non-medical Financial Assistance, Support Services, and Educational Materials. See further details in the Support Group section of this binder.

As a parent or family member, you will be required to assist in your child's care as well as help your child cope with cancer. In this most difficult role, you may need help adjusting to and coping with your own feelings.

The Child Cancer Fund can help. Please take advantage of the many programs and services we provide to help you through this time in your life. Contact us through Helena Gutierrez-Richards, LCSW, Pamela Bowers, LCSW, or Kristin Saunders, LCSW, Oncology Social Workers at Nemours Children's Specialty Care at (904) 697-3789 or Kim Taylor, LCSW, Social Worker at Wolfson Children's Hospital at (904) 202-0422.

On behalf of the Board of Directors, best wishes to you, your child and your family.

Sincerely,

A handwritten signature in black ink that reads "Carla Montgomery".

Carla Montgomery  
Executive Director



## Contact List



807 Children's Way  
Jacksonville, FL 32207  
[nemours.org](http://nemours.org)

### Doctors

**Paul A. Pitel, MD**

*Chair, Department of Pediatrics*  
P 904.697.3561  
F 904.697.3946

*Pediatric Hematology/Oncology*  
P 904.697.3793  
F 904.697.3792  
CLINIC 904.697.3789

**Howard Katzenstein, MD**

*Division Chief*  
*Pediatric Hematology/Oncology*

**Scott M. Bradfield, MD**

*Associate Division Chief*  
*Pediatric Hematology/Oncology*

**Eric Sandler, MD**

*Pediatric Hematology/Oncology*

**Cynthia Gauger, MD**

*Pediatric Hematology/Oncology*

**Michael J. Joyce, MD, PhD**

*Pediatric Hematology/Oncology*  
*Medical Director Pediatric*  
*BMT Program*

**Manisha M. Bansal, MD**

*Pediatric Hematology/Oncology*

**Allison Bechtel, DO**

*Pediatric Hematology/Oncology*

**Lisa M. Schilling, PhD**

*Licensed Psychologist*  
*Psychology & Psychiatry*  
P 904.697.3785  
F 904.697.3512

### Nurses

*Pediatric Hematology/Oncology*  
P 904.697.3789  
F 904.697.3790

**Sally Hendricks, RN, BSN**

*Nurse Manager*

**Katie McGill, RN, BSN****Cindi Kiddey, RN, BSN****Jessica Terrell, RN, BSN****Denise Hamer, RN, BSN****Tori Hutsell, RN, BSN****Alix Eckstein, RN, BSN****Tonya Condit, RN, BSN****Whitney Wilkinson, RN, BSN**

### Nurse Practitioners

**Cara Rapson, ARNP**

*Pediatric Hematology/Oncology*  
P 904.697.3789  
F 904.697.3792

**Lauren Mobley, ARNP**

*Pediatric Hematology/Oncology*  
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### Social Services

**Helena Gutierrez Richards, LCSW, ACSW, OSW-C**

*Clinical Social Worker*  
*Pediatric Hematology/Oncology*  
P 904.697.3786  
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[Helena.richards@nemours.org](mailto:Helena.richards@nemours.org)

**Pamela Bowers, LCSW**

*Clinical Social Worker*  
*Pediatric Hematology/Oncology*  
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F 904.697.3790  
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**Kristin Saunders, LCSW**

*Clinical Social Worker*  
*Pediatric Hematology/Oncology*  
P 904.697.3051  
F 904.697.5412  
[Kristin.saunders@nemours.org](mailto:Kristin.saunders@nemours.org)

### Child Life

**Joli Craver, BS, CLS**

*Pediatric Hematology/Oncology*  
*Child Life Specialist*  
P 904.697.3908  
F 904.697.3790  
[Joli.craver@nemours.org](mailto:Joli.craver@nemours.org)

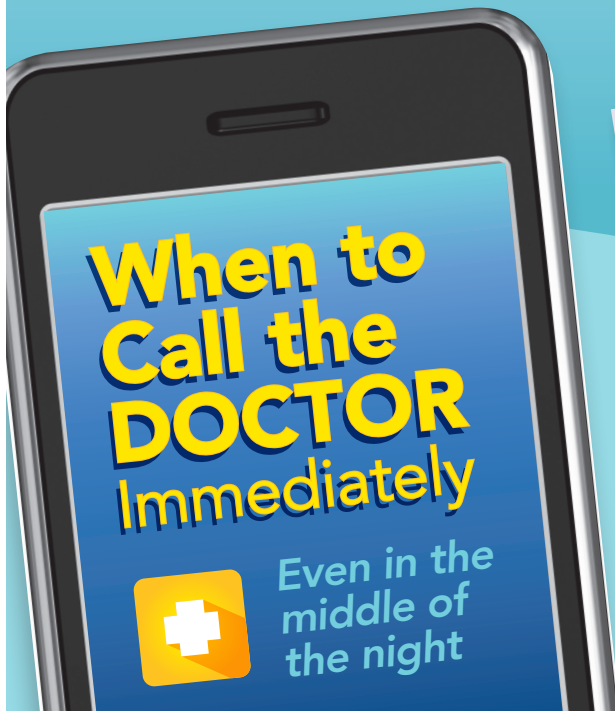
# A FEVER IS AN EMERGENCY!



EMERGENCY 101°+ (FEVERS)

If Your Child has a Fever  
101° or above

Call the Doctor *Immediately* ...



## EMERGENCY?

**Remain Calm,  
Follow Your Doctor's  
Instructions & Bring  
Your Emergency  
Pocket Guide With You.**

Stress from emergencies, including fevers 101° or above, can cause us to forget things. It's ok, you've prepared ahead of time. Your quick reference guide has many answers in one place. Keep it with you to help the hospital staff provide your child with safe & effective treatment.



**OH YEAH!  
Don't forget the  
EMLA™ Creme!**

## **Bill of Rights**

**David Callan, MSW**

### **For Cancer Patients**

- I have the right to be told the truth about my disease
- I have the right to feel bad if I receive bad news
- I have the right to talk to my doctor and my family about my cancer. And I have the right to privacy in refusing to talk to others about it if that is my choice.
- The fact that I am sick does not give others the right to make decisions for me. I have the right to be treated as a person and not merely as the “patient” while I am sick.
- I reserve the right to think of other things besides my cancer. I do not have to allow cancer to control every detail of my life.
- I have the right to ask others for help in the things I cannot do for myself, within reason.
- I always have the right to hope-whether for a full cure, a longer life, or a happier life here and now.
- It is O.K. to be angry at people I love. My anger does not mean I have stopped loving them
- I have the right to cope with my cancer in my own way, and my family has the right to cope with it in theirs. Our ways may be different, but that is O.K.
- I have the right to be free of pain if that is my choice.

### **For Family Members**

- I have the right to enjoy my own good health without feeling guilty. It is not my fault that someone I love has cancer.
- I have the right to choose whom I will talk to about the cancer. If I hurt others’ feelings because they are asking too many questions, it is not my fault.
- Even if I am a child, I have the right to know what is going on in our family. I have a right to be told the truth about the cancer in words I can understand.
- I do not always have to agree with someone just because he or she has cancer. I can get angry at the patient without always feeling guilty, because sickness does not stop someone from being a real person.
- I have the right to feel what I feel now, not what someone else says I “should” feel.
- I have the right to look after my own needs, even if they do not seem as great as the patient’s. I am permitted to take “time out” from the cancer without feeling disloyal.
- I have the right to get outside help for the patient if I cannot manage all the responsibilities of home care myself.
- I also have the right to get help for myself, even if others in my family choose not to get help.
- No one has the right to take my hope away. I believe that the powers that control life are greater than the understanding of any person or group of persons.

*Originally published by Cancer Family Care, Inc. Reprinted by permission from **The Candlelighters Quarterly Newsletter***



## PARENT HANDBOOK

As parents, you play an important role in helping your child. The information gathered in this handbook is the latest about cancer, its effects and treatment. We realize the information here is new and may seem overwhelming. Feel free to ask questions until you understand all that is happening. Although we are aware that this resource will not answer all of your questions, we hope the material provided will give you some guidelines.

### WHEN TO TELEPHONE

Deciding when to call the doctor can be very confusing. Here are some guidelines.

### CALL THE DOCTOR IMMEDIATELY (EVEN IN THE MIDDLE OF THE NIGHT),

If your child exhibits any of the following:

- **fever of 101 or above by mouth, ear or under the arm** (Do NOT take a rectal temperature)
- vomiting more than twice in one hour or once an hour over a period of 3 hours.
- bleeding you are unable to stop
- chicken pox

### OTHER SYMPTOMS TO REPORT TO THE CLINIC ARE:

- mouth sores
- earache, cold, flu, or sore throat
- constant headache, rash, or itching
- redness or swelling at injection site
- fainting
- increase in bruising, paleness, or petechiae (pinpoint purple-red spots on the skin)
- pain during bowel movement or urination
- infected hang nail or ingrown nails
- no stool (bowel movement) for two days
- excessive thirst or urination, especially while on prednisone
- check with clinic before undergoing any dental cleaning, treatment, or other procedures
- check with clinic before getting any vaccinations



### FEEL FREE TO CALL ABOUT ANY OTHER SIGNS, SYMPTOMS, CONCERNS, OR QUESTIONS.

Your doctor or nurse may be reached Monday through Friday, 8 AM to 4:30 PM, by calling the clinic at **(904) 697-3789** or 1-800-767-5437 (1-800-SOS-KIDS and ask for X3789) for long distance calls. After hours, weekends and holidays call **(904) 697-3600** or 1-800-767-5427 (1-800-SOS-KIDS). Ask for the doctor on call for the Hematology/Oncology clinic.

### IMPORTANT TELEPHONE NUMBERS

Baptist Medical Center .....	904-202-2000
Wolfson-4 Weaver Tower .....	904-202-0460
BMC – Pediatric Emergency Room.....	904-202-9000
<b>Nemours Children's Specialty Care (after hours, weekends &amp; holidays).....</b>	<b>904-697-3600</b>
Long Distance (toll free).....	1-800-767-5437
<b>Hematology/Oncology Clinic .....</b>	<b>904-697-3789</b>
<b>(Monday - Friday, 8 AM – 5:00 PM)</b>	

## **Multi-Disciplinary Health Care Team**

We provide the best care for your family by bringing together the skills and talents of many health care specialists.

The Pediatric Oncology Multidisciplinary Health Care Team is made of doctors, nurses, social workers, psychologists, dietitians, child life specialists, pharmacists, clergy and other child specialists. Patient care is provided at Wolfson Children's Hospital (WCH) and Nemours Children's Specialty Care (NCSC).



At Nemours Children's Specialty Care is where most of the outpatient care is provided. The physicians practice at both Wolfson Children's Hospital and Nemours Children's Specialty Care. Other staff members, however, have constant communication and frequent meetings to be certain everyone is kept informed of your child's medical needs. This helps keep all team members informed of your child's condition and treatment plan. All members of the health care team will work with you, as needed, throughout your child's treatment.

The Pediatric Oncology Team is dedicated, knowledgeable and ready to provide the best care possible.

**Hematology/Oncology (Attending Physicians):** The physicians are board certified in Pediatric Oncology. They specialize in the study and treatment of children with cancer and blood disorders. They will supervise your child's treatment

Manisha Bansal, M.D.	Division of Hematology/Oncology, NCSC
Allison Bechtel, D.O.	Division of Hematology/Oncology, NCSC
Scott Bradfield, M.D.	Associate Division Chief, Division of Hematology/Oncology, NCSC
Cynthia Gauger, M.D.	Division of Hematology/Oncology, NCSC
* Namra Tariq, M.D.	Division of Hematology/Oncology, NCSC
Michael Joyce, M.D., Ph.D.	Division of Hematology/Oncology, NCSC Medical Director, Bone Marrow Transplant Program
Howard Katzenstein, M.D.	Chief, Division of Hematology/Oncology, NCSC
* Darren Klawinski, M.D.	Division of Hematology/Oncology, NCSC
Paul Pitel, M.D.	Chair, Department of Pediatrics, NCSC
Eric Sandler, M.D.	Division of Hematology/Oncology, NCS

\* *Fellow: A physician who has completed medical school, internship and residency and is doing further study to become a specialist.*

**Other Medical Staff:** There are doctors in other specialty areas that you may meet while your child is being treated at WCH and NCSC.

Residents from University of Florida rotate through Wolfson Children's Hospital and Nemours Children's Specialty Care. They are doctors that have finished medical school and are specializing in the care of children. They will often see your child before the attending physician. The residents and attending physician will discuss your child's care.

**Radiation Oncology Physicians:** We have many options available for the child who needs radiation therapy. Our excellent radiation therapists meet with us on a regular basis to determine the

best type of radiation therapy to give to your child. Our radiation therapists include Drs. Olson and Anderson from Baptist Medical Center and Drs. Julie Bradley, Danny Indelicato, Ronny Rotondo, and Brad Hoppe from the University of Florida Proton Therapy Institute.

**Clinical Nurse Navigator:** Our Clinical Nurse Navigator is a registered nurse with advanced educational and clinical experience. She assists with your child's evaluations and disease related education and hospital admissions. Cindy Clough, MSN, RN, CPON – 4 Weaver Tower, Wolfson Children's Hospital.

**Nurse Practitioners:** Our nurse practitioners are master's prepared nurses who are certified as a pediatric or family nurse practitioner. Cara Rapson, ARNP and Lauren Mobley, ARNP assist our physicians with the care of patients admitted to WCH.

**Long Term Follow-Up Nurse:** Children are transitioned to this program once they are at least two years off treatment. The purpose of the LTFU program is to monitor your child for any possible late effects of their treatment and to focus on general health issues. The goal is for your child to stay as healthy as possible.

**Management Team:** The management team is available to you if you have any questions or issues about the care your child is receiving. Please contact:

#### **4 Weaver Tower, Wolfson Children's Hospital**

Jennifer Ellison, MBA, BSN, RN, CPHON – Nurse Manager  
Carie Murphy, BSN, RN, CPON – Assistant Nurse Manager 7a – 7p  
Christina Baten, BSN, RN – Assistant Nurse Manager 7a – 7p  
Dana Tyree, BSN, RN, CPON – Assistant Nurse Manager 7p – 7a  
Blair Anderson, BSN, RN, CPHON – Assistant Nurse Manager 7p – 7a  
Marie Stevenson, MSN, RN, CPN – Clinical Resource Nurse  
Cindy Clough, MSN, RN, CPON – System Educator



#### **Nemours Children's Specialty Care Hematology/Oncology**

Sally Hendricks, BSN, RN – Nurse Manager

**Staff Nurses:** Our registered nurses specialize in working with children who have cancer and blood diseases. There are many nurses who will care for your child when he/she is in the hospital. The out-patient nurses will coordinate your child's care each clinic visit, administer medications and/or chemotherapy, and provide ongoing teaching about your child's disease and treatment.

#### **Pediatric Bone Marrow Transplant Coordinators**

Annette Velez-Tirado, MBA, BSN, RN, CPON – Nemours Children's Specialty Care – 904.697.3992

Renee Liggers, BSN, RN – Nemours Children's Specialty Care – 904.697.3992

**Health Unit Coordinators (HUCs) and Nursing Service Technicians (NSTs) and Medical Assistants (MAs):** The HUCs, NSTs and MAs help patients, nurses and doctors with treatments and procedures.

**Pharmacist:** Our pharmacist prepares chemotherapy medications and other medications prescribed by your doctors. They also monitor for medications that interfere with each other, and work to identify, prevent, and resolve any medication related problems.

John Ng, PharmD – Wolfson Children's Hospital  
Tosha Egelund, PharmD - Wolfson Children's Hospital  
Bryan Blackwelder, PharmD – WCH Pediatric Clinical Coordinator

**Psychology:** Psychologists are specialists who provide the following psychological assessment and treatment services, both on an inpatient and outpatient basis, as well as research and educational activities:

Psychotherapeutic intervention

- Assessing and treating difficulties with treatment, such as taking medications and coping with medical procedures.
- Assessing and treating emotional difficulties that may complicate treatment, such as anxiety, depression, or behavior problems.

Psychological testing, as indicated

- Developmental assessment of children 0-5.
- IQ/academic assessment of school age-children (6-18), including assessment of learning difficulties, attention problems, and memory. Psychologists will work with the child's school to coordinate any educational services that may be needed.

Consultation with a Nemours child psychiatrist is also available, if medication is needed in addition to therapy.

Lisa Schilling, Ph.D., Nemours Children's Specialty Care  
(Services are also provided by Post-Doctoral Fellows and advanced graduate students supervised by Dr. Schilling).

**Clinical Social Workers:** The social workers will coordinate and assist you with psychosocial needs.

- Counseling for your family.
- School issues, including homebound/hospital bound programs.
- Family programs, financial assistance, community referrals, home health services.
- Parent support programs.

Kim Taylor, LCSW – Wolfson Children's Hospital  
Helena Gutierrez-Richards, LCSW – Nemours Children's Specialty Care  
Pamela Bowers, LCSW – Nemours Children's Specialty Care  
Kristin Saunders, LCSW – Nemours Children's Specialty Care

**Dietitians:** The dietitians work to meet your child's individual nutritional needs. They will answer any questions you might have about nutrition for your child.

Jodi Brindisi, RD, LDN – Wolfson Children's Hospital  
Elizabeth Bobo, MS, RD, LDN – Nemours Children's Specialty Care

**The Child Life Department:** The Child Life Departments at Wolfson Children's Hospital and Nemours Children's Specialty Care are a professional service designed to bridge the gap between hospital, clinic and home. The goal of the Child Life Program is to assist children and their families in coping with the emotional and developmental stresses of hospitalization. By providing opportunities for play, learning, preparation, self-expression, family involvement, socialization, and mastery, Child Life Specialists strive to minimize the stressful and potentially negative impacts of hospitalization and to maximize opportunities for positive and supportive experiences. The Child Cancer Fund provides a grant to Nemours Children's Specialty Care for the Child Life Specialist position.

Joli Craver, BS, CLS – Nemours Children's Specialty Care  
Christine Licsko, BS, CLC – Wolfson Children's Hospital

**Music Therapy:**

Music therapy services are available to all pediatric oncology patients and their families to facilitate pain reduction, socialization, self-expression, coping within a medical environment, and procedural support. Patients and families often find music therapy to be a beneficial and fun addition to their health services, encouraging positive interactions and engagement during appointments or hospitalizations. Board certified music therapists tailor each session according to age, diagnosis and musical preference to create opportunities where patients gain mastery over medical experiences to enhance emotional and physical well-being. Music therapy is available at Nemours Children's Specialty Care Jacksonville and by referral at Wolfson Children's Hospital.

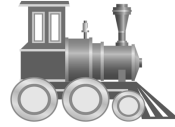
Steven Amburn, MT- BC - Nemours Children's Specialty Care Jacksonville  
Julie E. Avirett, MM, MT- BC - Wolfson Children's Hospital – 904.202.8543

**Pastoral Care:** A Chaplain is on staff at Wolfson Children's Hospital for your spiritual needs. A 24-hour chapel is located on the first floor of Baptist Medical Center to visit as you wish.

Sharon Eddins, M.Ed, Chaplain, Wolfson Children's Hospital

**Other Health Care Team Members:** You may meet many other health care team members during your child's treatment. Some of these are: Occupational Therapists, Respiratory Therapists, Speech and Hearing Therapists, Pet Therapy, Physical Therapists, Radiology Technicians, and Volunteers / Volunteens.

## **Nemours Children's Specialty Care – Outpatient Unit**



- The outpatient clinic is open Monday-Friday from 8:00 AM-5:00 PM. You may call (904) 697-3789 or 1 800-SOS-KIDS (ext. 3789) to speak to someone in the clinic. The phone calls are prioritized. Since patient care is ongoing everyday, you might not be able to speak with a doctor or nurse immediately.
- You will be able to reach the Oncology doctor on-call after hours, on weekends, and on holidays at (904) 697-3789 or 1-800-SOS KIDS. Ask the operator to beep the Oncology doctor on-call. You should receive a phone call back within thirty minutes. If not, call again.
- The “KidsWalk” connects Nemours Children's Specialty Care and Wolfson Children’s Hospital. An elevator is located on the Weaver Tower first floor for access to the walk. The KidsWalk is closed nightly at 6pm and all weekend.
- Call your primary care physician or case manager before your visits to Nemours Children's Specialty Care. The staff at Nemours will help by providing any information needed for your child’s medical care. It is ultimately **your** responsibility to get authorizations for your visits. Be sure to bring all insurance cards or Medicaid cards with you to your first visit. You will be asked to provide a lot of information at your first visit (insurance, address, emergency contacts, etc.). Follow-up visits will only require changes of that information. It is very important to give updated information so that we can communicate with you and your insurance provider.
- On your visit, you should park in the Nemours parking garage. Proceed to the eighth floor of the clinic and check in at the reception desk. Any co-pays will be collected at that time. If labs or x-rays are needed before you see the doctor, you will be given the instructions from the receptionist. After your first visit, you may also use the Kiosk located on the 1<sup>st</sup> floor to check in.
- Please bring any medications that your child is taking in their containers to every visit. This will help us to make sure that your child is receiving the right medication and dose. Child Cancer Fund provides a bag for your convenience.
- If your child is sick, has any kind of rash, or has had a direct exposure to someone who has chicken pox, notify the clinic **before** arriving so that your child can be properly screened.
- We try hard to stay “on schedule” during clinic. You can help us by being on time for your appointment. The length of your visit will depend on your child’s need for lab work, transfusion or chemotherapy administration. Emergencies, waiting for lab results, or unexpected needs for blood may happen, so be prepared (i.e. have snacks, extra diapers, formula, etc.). If you have questions about your wait time, please ask the Medical Assistant.
- When your clinic visit is complete, you will be given an “after visit summary” and your next appointment will then be scheduled.

## **Wolfson Children's Hospital - Inpatient Unit**



### **Family Room**

- An area for families to gather, socialize, have family dinners located on the back hallway of Weaver Tower 4
- The room is furnished with a small sofa, television, sitting chairs, and table and chairs for dining
- Equipment for patient/family use include; a sink, microwave, coffee maker, ice and water machine
- Volunteer groups stock the room with snack foods one to two times each week
- A cell phone charging station contains numerous charging devices for use
- We ask no overnight sleeping in the room
- Be thoughtful of others by cleaning up after yourselves and taking snacks for your child or family members only as needed

### **Patient Rooms**

- Patient rooms are all private and are equipped with a bathroom and a small refrigerator.
- All patient rooms are equipped with the Get Well Network which allows you to watch movies, play video games, place requests for food, send out kudos for special caregivers, along with other features. All are equipped with a television and receive basic cable service; including the Disney Channel (guides are available on the unit).
- Each patient room is equipped with a sofa bed that may be used as a bed for a parent or parent substitute (18 years or older) staying overnight.
- Personal items may be brought from home to make your child more comfortable during his/her stay. LABEL ALL ITEMS WITH YOUR CHILD'S NAME.
- Rooms should be kept tidy and neat.



### **Timmy's Playroom**

- Playgroups, which include medical play, crafts, or games are held from 10:00 AM – 12:00 Noon, Mon through Fri. It includes a PlayStation 3 and an IPAD. With nursing approval, the playroom is open seven days a week 7:00 A.M. to 9:00 P.M.
- We ask that all children under the age of 10 be supervised while in the playroom.
- Children without temperatures 101 or greater for 24 hours and those that are not in any type of isolation, may go to the playroom. Adult supervision is always necessary.
- Siblings are only allowed in the playroom with adult supervision and if they have been screened by our staff. This is to ensure they are not ill and a possible harm to the other patients on the unit.
- Since we would like to maintain the playroom as a "safe" place for our patients we do not allow unpleasant medical procedures to be performed on your child while he/she is in the play area.
- If your child is unable to physically come to the playroom please feel free to take any toys or games back to your child's room for his/her benefit and enjoyment.
- For children isolated to their rooms, you may take age appropriate toys to the room for play. Please do not return these toys to the playroom until a staff member has properly cleaned them.
- For sanitary reasons and because many of our patients are unable to eat, we do not allow food of any kind in the playroom except during special events.

### **Teen Room**

- The teen room contains video games, a stereo, TV, XBOX 360, XBOX 360 connect, Wii, Touch 2 play, 2 IPADS, and a Foosball table. These items are for patient use and provide an opportunity for learning and normalization during hospitalizations.

### **Telephones**

- The rooms are all equipped with a telephone. Phones should not leave rooms or be "switched".
- Local calls may be made at any time by dialing "9" and then the number. Long distance, collect or credit card calls should be directed through the hospital operator by dialing "0". The hospital operator will instruct you on the procedure for long distance calls.
- Calls to the patient rooms during the hours of 10 p.m. and 7 a.m. will be directed to the Nursing Station by the operator. If emergent or confirmed by a parent, staff will transfer call into the room.
- If you would like quiet time, disconnect the phone by unplugging it.
- The hospital will not accept collect calls.

### **Call Lights**

- All rooms are connected to an intercom system through the call light handset at the bedside. By pressing the button on the handset, a signal is sent to a centrally located panel. Your call is then answered by the staff.
- Red emergency call lights are located behind the beds and in the bathrooms. These red emergency buttons should be used for emergency assistance only!

### **Unit Galley Kitchen**

- For infection control purposes, we request that you do not enter the unit galley kitchen.
- Snacks and refreshments are provided for patient use only.
- Formula and baby bottles are available. Plastic baby bottles are also provided. Please check with your nurse for any diet restrictions.

### **Visitation**

- Parents may visit a child at anytime. Only two visitors are allowed in your child's room at a time.
- Visiting hours for all other individuals to the Children's Hospital are from 8 AM to 8 PM. After 8 P.M., a pass must be obtained from security to re-enter the hospital. A "pass station" is set up at the entrance from the parking garage. The guard will call the floor before allowing visitors to enter. If you are expecting someone, please notify the staff.
- No pets are allowed.
- During flu season (Oct. 1-April 30) children under the age of 5 are requested not to visit in order to prevent the spread of the flu (younger children have a greater incidence of carrying the flu).
- One parent or parent substitute 18 years or older may spend the night with the child.
- Sibling visits should be arranged with your child's nurse. All children will be screened prior to visitation. **Children under 18 should not be left unattended or use the playrooms without adult supervision.** Siblings should not spend the night or be left unattended in the playroom.

### **Patient & Family Centered Rounds**

We feel very strongly that our patients and their caregivers are an integral part of our Hematology/Oncology team. Monday through Friday, each morning, the physician and team will make rounds on each patient on the Hematology/Oncology service. Your nurse will ask you if you and your child would like to participate in rounds. If you desire to participate, when the team reaches your child's room, they will invite you to join them to discuss your child's plan of care. If you do not wish to participate, just let your nurse know.



### **Bedtime**

Bedtime is encouraged by **8:30 p.m.** The children do not have to be asleep at this time, but they need to be in their own rooms and engaged in quiet activity only.

### **No Smoking**

- Baptist Health and WCH are non-smoking facilities.
- There is no smoking anywhere on the campus, including the parking
- garages. You must leave the campus to smoke.



### **Safety**

- For your child's safety, children **under 2** will be placed in a **crib**. Children aged 3-4 may be placed in a toddler/youth bed if one is available. Children age 5 and over will be in a regular bed.
- Your child's bedside rails should be up at all times when you are not in the room.
- No fresh flowers or plants are permitted on the Hematology/Oncology Unit as part of neutropenic precautions.
- **No latex** balloons as many children and adults are allergic; Mylar balloons are allowed.
- Non-slip slippers or shoes must be worn by patient and all visitors to avoid falls.
- Please be courteous to other children on the unit. Keep noise level to a minimum.

### **Wolfson Children's Hospital is a designated Hit Free Zone**

- This is an important program to promote a safe and caring environment for all patients, families, and staff at Wolfson Children's Hospital.
- There are always options to spanking or hitting and we encourage you to make the best decisions about what will work for your child and family.
- Information including typical behaviors at each child's age and techniques for dealing with challenging situations will be made available.

### **Chemotherapy**

- For chemotherapy to start the day of admission, the patient must be on the unit by 5:00 p.m.
- During chemotherapy infusion, patients are required to stay on the unit, unless accompanied by staff.

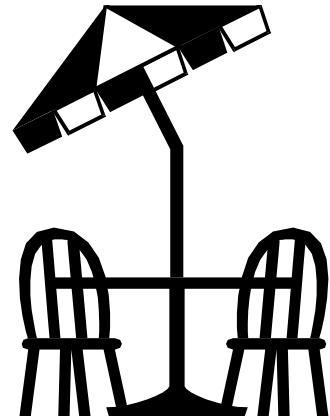
### **Meals**

- Meals ordered by the physician are provided and delivered to the patient's room.
- Meals are pre-selected. Notify the staff if the food is inappropriate for your child.
- When approved by your child's physician and after an order is written on his or her chart, your child may accompany you off the unit for meals.
- Meals are not provided for parents.
- Special orders can be requested through the Get Well Network.

## **Restaurants**

Family members and visitors have the following choices:

- |                         |   |
|-------------------------|---|
| Cafeteria:              | Located on the eighth floor of the Baptist Medical Center Tower.<br>Open: 7 AM – 2 PM Monday – Friday                     |
| Bridges Café:           | Located on the first floor of Wolfson Children's Hospital.<br>Open: 6 AM – 1 AM Seven Days A Week                         |
| Chick-fil-A Restaurant: | Located on the first floor of the Howard Building, adjacent to the Pavilion Building<br>Open: 6 AM – 4 PM Monday – Friday |
| Starbucks:              | Located inside Bridges' Café<br>Open: 6 AM – 2 PM Monday – Friday   |



Some local Restaurants deliver to the unit (pizza, for example), but not all do, so please inquire when ordering by phone.



## Our Mission

Ronald McDonald House Charities of Jacksonville supports the health and well-being of children by providing lodging, meals, transportation and a community of care to critically ill children and their families who need to be near a hospital for treatment.

## Ronald McDonald House

Ronald McDonald House Charities of Jacksonville's newly expanded 53-bedroom House is conveniently located near Jacksonville's top pediatric healthcare providers in the Historic San Marco community.

Families staying at Ronald McDonald House® of Jacksonville enjoy private and secure accommodations, nutritious meals prepared by community volunteers, access to technology, indoor and outdoor play areas, a fully stocked pantry, transportation to local hospitals and the comfort and affection of REED, the House's Facility Dog. In addition to serving as the Facility Dog, REED serves as an ambassador of Ronald McDonald House® of Jacksonville, using his role to share Ronald McDonald House's mission throughout the community. Ronald McDonald House provides a community of compassionate care, minimizing the effects of anxiety and fear of having a sick child. This special community of young families temporarily displaced from their home is an inclusive community where relationships support the enormous challenges the families are facing.

Ronald McDonald House Jacksonville requests that each family contributes to their stay. There is a suggested donation of \$20 per night. However, no family is ever turned away due to their inability to pay.

## Additional Services

Recognizing the need for expanded services, Ronald McDonald House has developed a Health and Wellness Initiative and an Education Initiative.

The Health & Wellness Initiative provides families with nutritional meals, nutrition seminars and cooking demonstrations by a resident Chef. The rooftop garden and fitness center combine with other programs to provide avenues that reduce the stress families often experience when caring for a critically ill child.

At the heart of the Ronald McDonald House Education Initiative is the KidZone Learning Center. This space is a place of learning and discovery that provides children the opportunity to engage in fun and interactive enrichment activities centered on science, reading, art, music and technology.

## Referrals

For first time guests, a referral must be made by a medical professional involved in your child's care. Criminal background checks are performed on all individuals, 18 years or older who plan to stay at Ronald McDonald House of Jacksonville.

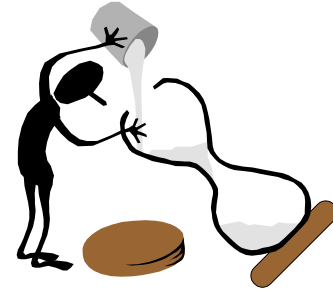
**Ronald McDonald House Charities of Jacksonville | 824 Children's Way | Jacksonville, FL 32207**  
**Phone: (904) 807-4663 | Fax: (904) 807-4700**

## **OVERVIEW OF CHILDHOOD CANCER:**

Cancer in children is still very rare in the United States. Each year in the US, approximately 150 out of every one million children under the age of 20 will be diagnosed with cancer. That means roughly 12,400 children and adolescents under age 20 will be diagnosed, of which, 8,700 will be under the age of 15 years (1999 SEER). (The incidence of cancer in adults is 1 in 3).

The cause of childhood cancer is still unclear. Cancer is rarely hereditary. It is **not** contagious. There is nothing that you or your child could have done to prevent their illness. There are, however, things that can be done to help control it.

Researchers are working together every day to find causes as well as cures for childhood cancer. Through research, the cure rate in childhood cancer has increased tremendously over the years.



Standard treatment for most types of cancer may include surgery, radiation therapy and chemotherapy. Treatment plans may combine one or more of these methods depending on the type of cancer.

## **Cooperative Groups**

- Cooperative cancer programs are designed to evaluate the latest concepts of chemotherapy, radiation therapy, surgery, immunotherapy, and stem cell transplant.
- The overall goal of cooperative groups is to increase the survival and cure rates of children with cancer.
- To achieve this, cooperative clinical trials of newly developed therapies and combinations of surgery, radiation, and chemotherapy are used.
- COG is a research group of doctors, nurses and scientists who strive to find the best treatments possible for childhood cancers.
- COG stands for Children's Oncology Group, and is supported by the National Cancer Institute and the National Childhood Cancer Foundation (NCCF).
- Nemours Children's Clinic/Wolfson Children's Hospital are one of over 240 COG affiliated hospitals who treat children with cancer.
- PBMTTC stands for the Pediatric Blood and Marrow Transplant Consortium.
- The PBMTTC is a group of physicians who specialize in treating children through blood and marrow transplants ("bone marrow transplants").
- It unites physicians from all over the world. Our participation in the PBMTTC assures that your child receives "state-of-the-art" care for his/her disease.

## **Protocols and Treatment Plans**

- A treatment protocol is a research study that is conducted with patient participation. Protocols are based on:
  - ♥ Treatment given other children
  - ♥ Research done by scientists and doctors
  - ♥ Close follow-up of other children with the same type of cancer
  - ♥ Information from COG doctors and other doctors around the world

- Whenever you are asked to participate in a research study, you will be given a verbal and written explanation of the purpose of the study. Take time to read the consent form and ask questions before deciding if you wish to participate.
- You will be given a copy of your child's treatment plan, also called a "road map". The road map tells you what tests and treatments are coming up in the weeks and months ahead. Tests and treatments are done according to this map, but changes may be made to better serve your child.
- Once your child is entered on a protocol, you still have choices. If the protocol is not in your child's best interest, the treatment can be altered, or your child can be removed from the protocol altogether. You may choose not to continue treatment on the protocol.
- Whether or not you decide to enroll your child on a treatment protocol, every attempt will be made to deliver the best known treatment to your child.





# What's Taking So Long?

*Why preparing your chemotherapy is not like preparing a milkshake...*

## Why does making a dose of chemotherapy take longer than making a milkshake?

**First, a mistake in making a milkshake is not harmful. But your chemotherapy is not a milkshake.** In making a milkshake, using vanilla ice cream instead of chocolate ice cream might not be what you want, but it will not harm you. With chemotherapy, there is no room for error. The pharmacist must be 100% correct, and accuracy takes time.

**Second, your milkshake must be clean, but it does not have to be germ-free. But your chemotherapy is not a milkshake.** Your chemotherapy must be germ free. It must be prepared in the biological safety cabinet using sterile supplies and using a special technique to keep it sterile.

**Third, if milkshake ingredients spill on the technician, it is messy and uncomfortable, but not harmful. But your chemotherapy is not a milkshake.** Most experts believe that it is unhealthy for health care personnel to be in regular contact with even small amounts of chemotherapy. The same chemotherapy that may prolong or save your life can harm someone without cancer.

## What's taking so long?

Chemotherapy is one of the main methods of treating cancer. But improperly made chemo-therapy won't help and can even be harmful.

Specially trained pharmacists and pharmacy technicians prepare chemotherapy.

A technician or pharmacist stands in front of a piece of equipment called a Biological Safety Cabinet to make chemotherapy. It's made inside this cabinet for two reasons. First, is to keep chemotherapy preparation sterile (germ-free). Second, is to limit contact between chemotherapy particles and pharmacy staff.

**All chemotherapy preparations must be sterile, accurate & timely.**

Sterile (germ-free) so you don't get infected by the chemotherapy when it goes into to your body.

Accurate so it is made exactly as your doctor orders. It must be the right drug, right dose and right fluids and the label must include all needed information.

Chemotherapy must be made in a timely manner that also guarantees sterility and accuracy. "Timely" does not mean "as fast as possible." It means in the least amount of time while still ensuring an accurate and sterile product.

### Additional Safety Precautions:

Each pharmacist processes one order at a time, so each order gets his/her full attention. When a pharmacist receives more than one order at the same time, the second order waits until the first is done. It's like waiting in line at the grocery store. Each clerk can only wait on one customer at a time.

**Special Note: It can take between 20-40 minutes to make one dose depending upon the type of chemotherapy. Some drugs are powders and need time to dissolve. Also, many patients receive more than one type of drug. It is not unusual for a patient to get up to six separate drugs.**

What's involved in making  
chemotherapy?

# The Steps...

*There are many steps involved in making your chemotherapy. Included are:*



**1. Doctor orders your chemotherapy**

Your doctor or nurse practitioner must assess your status, your blood work, and your body's ability to handle chemotherapy before he/she orders a treatment. Your doctor or nurse practitioner prescribes the drug, dose, dates of treatment, method of administration, type of fluid to contain the drug, and duration of treatment.

**2. Nurse reviews the order and delivers it to the pharmacy**

After your doctor or nurse practitioner writes the order, your nurse reviews the order for completeness. The nurse then delivers the order to the pharmacy.

**3. Pharmacist reviews the order for accuracy & completeness**

The pharmacist reviews the order completely, and then recalculates the dose. Then the pharmacist must determine the amount and type of IV fluids to put the chemotherapy in and how fast to safely infuse it.

**4. Pharmacist enters the order into the computer system**

Pharmacist types the order into a computer system. The computer system then prints a label, which is eventually attached to the bag or syringe of chemotherapy. After the order is entered, the entry is double checked by a second pharmacist.

**5. Technician reviews the label and gathers the supplies**

To make the chemotherapy in the Biological Safety Cabinet, a technician gathers the supplies, including needles, syringes, alcohol wipes, and containers of chemotherapy. These containers are called vials.

If the drug comes as a powder, the technician adds another solution to dissolve the powder. The technician uses a syringe to remove the exact amount of chemotherapy from the vial, then adds chemotherapy to a bag of fluid or to a syringe and places the label onto the bag or syringe.

## What happens after the chemotherapy is prepared and checked?

After the drugs are prepared and checked in pharmacy, two nurses check the calculations and perform a final double check to make sure that it's your chemotherapy and that the label matches your doctor's order.

## Why can't the chemotherapy be ordered and prepared ahead of time?

Your doctor or nurse practitioner may need to examine you and look at your lab values before he/she orders the chemotherapy. Based on this examination, he/she decides if you should receive a different dose of the same drug, a different drug, or perhaps receive no treatment at all. Therefore, the chemotherapy cannot be made until your doctor or nurse practitioner sees you and checks the lab values.

**Please remember.** "Timely" does not mean "as fast as possible." Timely means as quickly as possible while still ensuring your chemotherapy is carefully made – that it is accurate, sterile and safe for you and the staff. Your patience is appreciated.

Sincerely, The Baptist Health and Wolfson Children's Hospital Healthcare Team



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## **MEDICATIONS:**

Giving medications to your child is a tough job at times. Children may not cooperate when taking medication. The repeated challenge, several times a day, day after day, may become exhausting and overwhelming. The following section will discuss the various ways of administration and some useful hints.

**CAUTION!** The same medication can come in different concentrations. ALWAYS check with your pharmacist and read the label each time you refill your prescription.

For routine medications, parents should always keep a one week supply on hand. Call the clinic or the pharmacist during business hours when more medication is needed.

### ***Infants and Toddlers:***

- Hold in a semi-reclining position, with head raised higher than the body.
- Place the dropper or syringe in the side of the mouth, not on the tongue. Slowly give small amounts, waiting for the child to swallow.
- You may try placing the syringe inside the mouth while the infant is sucking on a nipple. This may be helpful in having the child swallow.
- Do not add medication to the infant's formula bottle.
- In order to make sure an uncooperative child safely receives his/her medication, the following steps may be helpful.
  - ◆ Place the child in your lap with the head slightly elevated, cradle in your arms.
  - ◆ Place the child's arm behind your back.
  - ◆ Use the hand of your arm that is cradling the head to hold the child's free arm.
  - ◆ While you have the child safely restrained, give the medication slowly into the child's mouth.

### ***School Age:***

- Always explain why the child is taking medication. It should never be a punishment.
- Always supervise your child while taking medication.
- Do not allow the child to be distracted during the medication time. Turn off the television, computer games, etc.
- Try to make a game out of taking the medication. Give the child praise.
- Allow the child to make choices. Let him/her choose which medication to take first, what drink to take with their medication, or that he/she may take medication on a count to "three".
  - Do not spend more than 2 minutes convincing your child to take his/her medication. Be clear with your expectation. You may give a small reward such as a sticker or special activity when the medication is taken.

### ***Teenagers:***

- Teenagers often need encouragement and supervision when taking their medication.
- Teenagers frequently skip taking medication because they forget or become tired of a routine.
- Find a time that may be convenient to remember, such as during meals or before bedtime.
- A written calendar may be helpful for your child to remember a schedule.



## **MEDICATION TYPES**

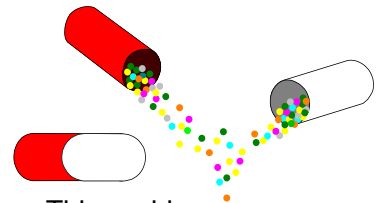
### **ORAL: LIQUIDS, TABLETS/CAPSULES, MOUTH RINSES**

#### **LIQUIDS**

- Oral medication (given by mouth) should never be given to any child while lying flat.
- Liquids are usually the easiest way to give a medication to children under the age of six years.
- Liquid medicine should be measured exactly.
- Use an oral syringe or medicine cup from your pharmacy or hospital. If specified, refrigerate the medication.
- Do not use a regular spoon; this is very inaccurate.
- You may use a measuring spoon, the type used for baking.
- Keep away from light.
- Ask your doctor, nurse or pharmacist if you may mix the medication in a drink or applesauce/pudding to disguise the taste if necessary. Use only a small amount of beverage to make sure the child gets all the medication.
- Wash and dry the oral syringe or measuring spoon after each use.

#### **TABLETS/CAPSULES**

- Many medications are made in tablet or capsule form.
- Some children prefer pills since they may not have a distinct taste.
- Always check first before crushing or dissolving pills. Crushing or dissolving the pill may change the way the body absorbs the medication. This could decrease the effectiveness of the medicine or be harmful to your child. Always check with your doctor, nurse or pharmacist first.
- Crush a pill by placing it between two spoons, or place in a small plastic bag and use a kitchen utensil to crush.
- Place the crushed pill in a teaspoon of liquid or food, such as juice, Jell-O, pudding, ice cream or peanut butter.
- You may try to break a pill in half. Smaller pieces may be easier for a child to swallow than a larger pill.



#### **MOUTH RINSES**

- Mouth rinses are used to keep the mouth clean.
- Some mouth rinses must be swished and spit out while others should be swallowed. Check with your doctor, nurse, or pharmacist.
- If your child is unable to swish the medication and swallow, use an oral syringe to place half the medication in each cheek.
- Wait 15-20 minutes before giving your child a drink or food after a mouth rinse. Drinking or eating immediately after the medication will wash it away and your child will not get the full effect.

#### **RECTAL SUPPOSITORIES**

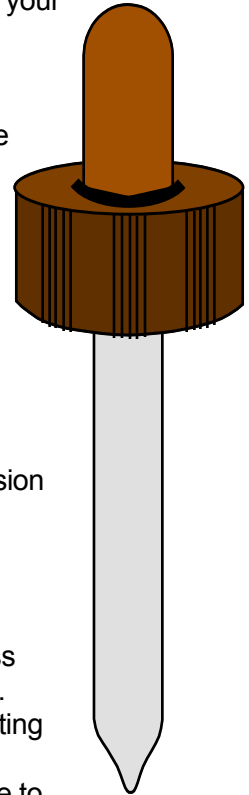
Medicines given rectally are not advised. Before giving any medication this way, check with your doctor or nurse.

## **EYE MEDICATION: DROPS, OINTMENTS**

Explain to the child what you plan to do. Although not painful, eye drops may be unpleasant and cause the child to unintentionally close his/her eyes. Place the infant or small child lying down on his/her back. The older child may sit up with head tilted back. Ask the child to look up. Use one hand to pull the lower lid down, making a little “cup”. With the medication in the other hand, rest this hand on the child’s head and apply the solution or ointment into the “cup”. By resting your hand on the child’s head you will move with the child should he/she move and avoid poking the child or dropping medication on his/her face.

Placing medication into the eyes of an infant may be difficult because they often close the lids tightly. You may place the drops in the corner of the eye near the nose when the baby’s eyes are closed. When the baby opens his/her eyes, the medication will flow into the eyes.

- If medication needs to be stored in the refrigerator, take it out at least one-half hour before using.
- Keep the medication sterile. Do not touch the tip of the bottle or tube with your hands or touch to the child’s eyes.
- If the child needs drops and ointment to the eyes, give the drops first then wait 3 minutes before placing the ointment in the eyes.
- If possible, give eye ointments before bed time or at nap time, since the child’s vision will be blurred for a while.



## **EAR MEDICATION: DROPS**

The child should lie flat on his/her back with head turned to the side. If the child is less than 3 years old, gently pull the ear back and down while placing the drops in the ear. Children older than 3 years should have their ear gently pulled up and back while getting their ear drops.

- Keep the child with head turned for approximately 2 minutes to allow the medicine to enter deep into the ear.

## **NOSE DROPS**

With the child lying on his/her back, place a pillow behind the shoulders. This will cause the child’s head to tilt back. Place the drops of medication into the nostrils. Do not put the dropper into the nose. Once the drops are in, the child should remain in the position with his/her head tilted for one minute.

## **SUBCUTANEOUS INJECTION**

Your child may require a subcutaneous injection at various times during therapy. A subcutaneous injection is given using a small needle placed under the skin. Subcutaneous injections will initially be given by a nurse. Eventually you will be taught the technique so that you can give them.

## ACETAMINOPHEN (Tylenol)

### What is it?

- Medicine used to control mild to moderate pain
- Medicine used to reduce fever

### What it looks like:

- Red, orange or purple liquid
- Pink, purple or white tablets

### How is it given?

- Orally

### Side Effects:

- There are rarely any side effects with Tylenol unless an overdose is given.

**\*\*\*\*\* Do not give Tylenol until first checking with your child's physician.**  
**\*\*\* Do not substitute aspirin or aspirin-containing product for Tylenol.**

### Common aspirin-containing products to AVOID include:

Alka-Seltzer	Equagesic
Anacin	Excedrin
Arthritis Pain Formula	Excedrin PM
A.S.A. Tablets	Fidrinol
Ascriptin	Goody's Powder
Aspergun	Measurin
Bayer Aspirin	Midol/Norgesic
B.C. Powder	PAC
Bufferin	Percodan
Butalbital Compound	Perisistin
Cama	Phenaphen
Congespirin	Propoxyphene Compound
Coricidin	Robaxisal
Cope	Sine-Aid – Chewable
Darvon Compound	Soma
Disalcid	St. Joseph
Doan's Pills	Stanback
Dristan Tabs	Talwin Compound
Ecotrin	Trilisate
Empirin Compound	Trigesic
	Vanquish

GRANISETRON HCL  
**(Kytril)**

**What it is:**

- Prevents nausea and vomiting during and after the administration of the chemotherapy.

**What it looks like:**

- Clear liquid
- Tablet

**How is it given?**

- Into the vein (IV) or venous access device
- By mouth

**Common side effects:**

- Few common side effects occur.
- Headache

**Less common side effects:**

- Drowsiness
- Diarrhea
- Constipation

**Special Instructions:**

- Kytril is given 30 minutes before the administration of the chemotherapy
- Notify physician if any side effects occur.

LIDOCAINE 2.5% and PRILOCAINE 2.5%  
**(Emla Cream)**

**What it is:**

- A cream which when applied to the skin produces a numbness which allows painless injections or minor procedures to be done.

**What it looks like:**

- A white cream

**Common side effects:**

- There may be mild local reactions to the drug such as: swelling, itching, paleness, rash or redness.

**Less common side effects:**

- Allergic reaction

**Special Instructions:**

- Apply at least 60 minutes before the planned procedure time
- Report any side effects to the physician/nurse.
- Application instructions as follows:
- Apply 1/2 the 5 g tube (approx. 2 in. by 2 in.) to skin in a thick layer at the port site. (If you are unsure of the location, arrive 30 minutes prior to appointment so that a staff member can assist you.)
- Cover area with Glad Press and Seal Plastic Wrap.
- Cover the EMLA<sup>®</sup> Cream so that you get a thick layer underneath. Do not spread out the cream. Smooth down the Press and Seal edges carefully and ensure it is secure to avoid leakage. (This is especially important when the patient is a child).
- The time of application can easily be marked directly on the occlusive dressing with a Sharpie. EMLA<sup>®</sup> must be applied at least 1 hour before the start of a routine procedure and for 2 hours before the start of a painful procedure.

The following step will be performed by a health professional:

- Remove the Press and Seal dressing, wipe off the EMLA<sup>®</sup> cream, clean the entire area with an antiseptic solution and prepare the patient for the procedure. The duration of effective skin anesthesia will be at least 1 hour after removal of the occlusive dressing.

**Precautions:**

- Do not apply near eyes or on open wounds
- Do not use in children under one month of age
- Keep out of reach of children

LIDOCAINE 2.5%

**(LMX Cream---available over-the-counter)**

**What it is:**

- A cream which when applied to the skin produces a numbness which allows painless injections or minor procedures to be done.

**What it looks like:**

- A white cream

**Common side effects:**

- There may be mild local reactions to the drug such as: swelling, itching, paleness, rash or redness.

**Less common side effects:**

- Allergic reaction

**Special Instructions:**

- Apply at least 30 minutes before the planned procedure time.
- Report any side effects to the physician/nurse.
- Application instructions as follows:
- Prepare the affected area by washing with mild soap and water. Do not use alcohol or acetone.
- Apply a small amount of cream and gently massage it into the affected area. Next, squeeze enough cream to completely cover the affected area so that no skin is visible under the cream.
- Cover the cream with Glad Press and Seal Plastic Wrap. Seal the edges so that there is no leakage.

The following steps will be performed by a health professional:

- Remove the Press and Seal dressing, wipe off the ELA-Max cream, clean the entire area with an antiseptic solution and prepare the patient for the procedure. The duration of effective skin anesthesia will be at least 1 hour after removal of the cream.

**Precautions:**

- Do not apply near eyes or on open wounds.
- Do not use in children under one month of age.
- Keep out of reach of children.

**ONDANSETRON HCL**  
**(Zofran)**

**What it is:**

- Prevents nausea and vomiting during and after the administration of chemotherapy.

**What it looks like:**

- Clear liquid (IV)
- Tablet
- Oral solution (light yellow)

**How it is given:**

- Into a vein or venous access device
- By mouth

**Common side effects:**

- Zofran has few common side effects
- Headaches may occur

**Less common side effects:**

- Constipation
- Abdominal pain
- Weakness
- Dry mouth
- Rare reports of tremors and twitching

**Special instructions:**

- The first dosage will be given ½ hour before the administration of chemotherapy. Check with the physician/nurse to see if this should be given at home by mouth or will be given IV in the clinic.
- Give Zofran as directed. Continue 1-2 days after completion of chemotherapy.
- Notify the physician immediately if any side effects occur.

## **About the Body and Bone Marrow**

- The HEART is a pump that moves or “circulates” blood to every cell and tissue in the whole body.
- The LUNGS move oxygen, which is food for the tissues, into the blood, and takes carbon dioxide, which is the waste from used-up oxygen, out of the blood.
- The LIVER and KIDNEYS act like waste control units by processing and getting rid of digested food or substances that could be toxic to the body.
- All of these organs and their systems function are vitally important. Many of the routine blood tests reflect the working of these systems.
- BONE MARROW is confined to the cavities of the bones and is where the blood cells are formed.
- The bone marrow contains special cells called stem cells, which produce red blood cells, white blood cells, and platelets. All of the bones in the body have bone marrow, but the bones with the greatest amount of bone marrow are the hip bones or iliac crests.
- All organ systems may be affected, but the four most common systems affected during treatment are the heart, liver, kidneys, and lungs.

## **BLOOD COUNTS**

- Bone marrow cells make our red blood cells (RBC's), white blood cells (WBC's) and platelets. Cells made by the bone marrow may be injured by chemotherapy and radiation because the chemotherapy and the energy particles cannot differentiate cancer cells from these good cells. Chemotherapy and radiation work by stopping or changing blood cell growth.
- We measure your child's blood counts using a test called a CBC (complete blood count). The blood counts will be checked once or twice a week or every other week while your child is receiving chemotherapy and more frequently if needed.

### **Red Blood Cells (RBC's)**

- Transports oxygen through the body and give us energy.
- When your child's RBC count is low he/she is considered anemic.
- If your child's hemoglobin and hematocrit drops below 7.0 and 21.0 respectively your doctor may order a blood transfusion.
- If your child is anemic, the blood is not able to carry enough oxygen to the tissues. You may notice some of the following symptoms:
  - paleness
  - lack of appetite
  - shortness of breath
  - dizziness
  - weakness
  - tiredness
  - irritability

- When your child is anemic:
  - ◆ Encourage frequent rest periods



### **White Blood Cells - (WBCs)**

- The WBC's are part of the IMMUNE SYSTEM which is responsible for defending the body against foreign substances and recognizing self from non-self.
- The white blood cells, thymus gland, spleen and lymph nodes, all work together to comprise the IMMUNE SYSTEM which is one of the most complex systems in the body.
- The WBCs fight infections. WBC's capture, destroy, and get rid of germs in your body. There are different kinds of WBCs.
- WBCs, Neutrophils and bands are the most important because they help protect the body from bacterial infections.



- When your child's WBC count is low, he/she is considered neutropenic. (susceptible to infections)
- The normal WBC count 4000-11000. For an immunosuppressed child, the normal WBC count is 2000-5000.
  - Kinds of WBC's
    - ◆ Polys (neutrophils or segs) – help fight bacterial infections
    - ◆ Bands – immature polys
    - ◆ Lymphocytes
    - ◆ Monocyte
    - ◆ Eosinophil
    - ◆ Basophil
- Absolute Neutrophil count (ANC)
  - ◆ Identifies susceptibility to infections; the lower the ANC, the greater the risk of infection
  - ◆ Normal X-ANC is greater than 1900
  - ◆ An ANC below 1000 is considered neutropenia
  - ◆ ANC 500-1000: your child is considered moderately neutropenic
  - ◆ An ANC less than 500: your child is considered severely neutropenic
  - ◆ An ANC less than 300: your child is very severely neutropenic
  - ◆ To calculate the ANC: Multiply the WBCs (move decimal point 1 place to right **or** multiply by 10) by the neutrophils (polys) + the bands.

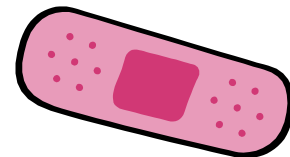
$$(\text{WBC} \times 10) \times (\text{Polys (neutrophils)} + \text{bands}) \text{ i.e.: WBC } 5.0, \text{ Polys } 30, \text{ bands } 0$$

$$(50) \times (30+0) = 1500$$

- Most children will be neutropenic at times throughout treatment. Your child's ANC may at times be zero. This is an expected occurrence while receiving chemotherapy.

### **PLATELETS (PLTs)**

- Helps the blood to clot normally.
- A platelet transfusion may be given when platelets are less than 10,000-15,000.
- A decrease in Platelets is called thrombocytopenia which may mean your child is at risk for abnormal bleeding and special precautions should be taken to decrease his/her activities at that time. When the platelet count is low notify the clinic if you notice the following signs:
  - ◆ Increased bruising
  - ◆ Petechiae (red or purple looking freckles or pinpoint bruises)
  - ◆ Bleeding from small cuts or scrapes that is hard to stop
  - ◆ Urine may become pink or red-tinged
  - ◆ Stools may have a red or black appearance
- When your child's platelet count is low, some precautions to follow include:
  - ◆ Avoid contact sports (football, Karate, etc.) or rough play (skateboarding, surfing, trampolines, ATVs) that could cause physical injury, especially to the head.
  - ◆ Clean teeth with a soft bristle brush, a tooth sponge, or a clean soft cloth to prevent irritation and bleeding of the gums (No dental appointments should be made when platelets are low)
  - ◆ No rectal temperatures or rectal suppositories because these could tear the lining of the intestines and cause bleeding.
  - ◆ If your child experiences bleeding, apply firm pressure to the wound. Any time bleeding is hard to control, immediately call your doctor.



## Complete Blood Count (CBC) Summary Sheet

<u>Cell type</u>	<u>Function</u>	<u>Normal</u>	<u>Decreased Level</u>	<u>When decreased what to look for</u>
White blood cells	Fight infection	9,000-11,000	<1,000	Fever 101 or greater, chills sweating, loose stools, burning when urinating, redness or swelling of cuts or sores
Red blood cells	Carry oxygen	HGB 11 HCT 30%	< 7 < 21 %	Increasing paleness, increasing tiredness, headaches
Platelets	Control bleeding	150,000 – 450,000	<15,000 - 10,000	Increasing bruising, gums bleeding, nose bleeding
Absolute Neutrophil Count (ANC)	Tells how well body fights infection	>1000	<1,000	Guard against infections, Maintain integrity of mucous membranes and skin Maintain adequate nutrition and fluid intake Avoid persons who have infections Report immediately any signs of infection Maintain personal hygiene Get adequate rest/rest

To calculate the ANC: Multiply the WBCs (move decimal point 1 place to right **or** multiply by 10) by the neutrophils (polys) + the bands.

(WBC x 10) x (Polys (neutrophils) + bands) i.e.: WBC 5.0, Polys 30, bands 0  
 $(50) \times (30+0) = 1500$

## **Tests and Procedures**

A variety of tests will be used to diagnose your child including the following:

### **Biopsy (needle)**

A method used to diagnose whether cancer cells are present

- A needle is inserted into the suspicious site and a sample is removed by aspiration
- The tissue cells are then examined for abnormalities
- Sedation may be used to help your child relax
- A local anesthetic may also be used to numb the needle insertion site
- Your child may feel pressure or discomfort when the needle is inserted
- A small dressing will be applied after the procedure is complete
- Your child may complain of soreness at the site following the procedure
- There are no restrictions once the test is complete

### **Biopsy (surgical)**

A method used to diagnose whether cancer cells are present

- A sample of the suspicious site is removed by surgical incision
- The tissue cells are then examined for abnormalities
- An anesthetic will be used so that your child will be asleep during the procedure
- Nothing to eat or drink is allowed for several hours prior to the procedure (usually after midnight the night before)
- The biopsy is performed in the operating room
- The incision site will be closed with several stitches
- A small dressing will be applied to the surgical site
- Your child may complain of soreness at the incision site following the procedure
- There are no restrictions once the test is complete

### **Bone Marrow Aspiration and Biopsy**

Bone marrow is the substance in the center of bones that produces white blood cells, red blood cells, and platelets

- During this procedure a sample of bone marrow is taken from the hip bone
- The sample is then examined for abnormalities or to monitor your child's response to treatment
- The procedure is usually done in the hospital
- Your child will be sedated using "managed anesthesia", a light form of sedation used so that your child is asleep during the procedure
- Nothing to eat or drink is allowed for several hours prior to the procedure (usually past midnight the night before)
- You may be present in the room until your child falls asleep unless the procedure is done in the operating room
- A needle is placed in the hip and a syringe is used to withdraw a sample of the bone marrow
- If a biopsy is done a small sliver of bone is taken from the same insertion site
- A dressing will be applied after the procedure is complete
- Your child may complain of soreness to the insertion site following the procedure
- There are no restrictions once the test is complete

### **Computerized Axial Tomography**

- A CAT or CT scan is an x-ray that takes pictures to provide imaging that helps diagnose disease and monitor the success of treatment
- The procedure is non invasive and painless
- Sedation may be used if needed to help your child remain still
- A contrast may be swallowed or injected into a vein in order to help visualize certain body areas
- Your child will be placed on an examination table for about 20 minutes while the pictures are being taken
- There are usually no restrictions before or after the test

### **Echocardiogram**

- An "echo" records movements of the hearts chambers and valves
- Used to show how well your child's heart is functioning and whether it is being affected by treatment
- Uses painless ultrasound waves without risk to your child
- A clear gel and a transducer will be placed on your child's chest
- The transducer will be moved around for about 10 minutes while the test is being performed
- There are usually no restrictions before or after the test
- Sedation may be used if needed to help your child remain still



### **Electrocardiogram**

- An EKG is a painless procedure that records the hearts rhythm and electrical activity
- Sticky pads called electrodes will be placed on your child's arms, legs, and chest
- Wires will be connected from the electrodes to a machine that will record your child's heart rhythm
- Your child will need to be still for about 10 minutes while the test is being performed
- There are usually no restrictions before or after the test
- Sedation may be used if needed to help your child remain still

### **Lumbar Puncture**

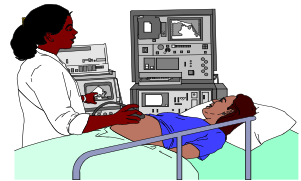
- A fluid surrounds the brain and spinal cord called spinal fluid or CSF
- A sample of CSF can be taken to determine whether any cancer cells are present or to monitor the progress of treatment
- Chemotherapy may be added to the CSF during this procedure in order to kill any cancer cells that might be present
- The procedure is usually done in the hospital
- Your child will be sedated using "managed anesthesia", a light form of sedation used so that your child is asleep during the procedure
- Nothing to eat or drink is allowed for several hours prior to the procedure (usually past midnight the night before)
- You may be present in the room until your child falls asleep unless the procedure is done in the operating room
- A needle will be inserted between your child's vertebrae into the spinal fluid
- The fluid will be collected and sent to the lab for analysis
- If your child needs chemotherapy it will be injected through the needle that is already in place
- A small bandage will be placed at the site once the needle is removed
- Some children may get a headache that can be prevented by lying flat for 30 minutes after the procedure
- There are no restrictions after the procedure is complete

### **Magnetic Resonance Imaging**

- An MRI is a safe painless test that provides detailed images of the inside of the body
- It is used to diagnose and monitor the progress of disease
- Your child will be placed inside a tunnel like machine that may produce anxiety
- The MRI machine will produce periodic thunder like noises while it takes pictures of your child's body
- A sedative may be used to help your child remain still and to decrease anxiety
- The procedure takes approximately 20 minutes to 1 hour
- There are usually no restrictions before or after the test
- Pregnant persons cannot be in the MRI room
- "MR-I Am Ready!" program offered for children 6 and older. Contact Child Life at 904-202-8548.

### **Nuclear Medicine Scans**

- These scans are safe and painless procedures that are used to evaluate the liver, brain, kidneys, bones, and other organs
- They use a radioisotope that is either swallowed or injected into a vein to look for abnormal masses
- Pictures are taken to see where the isotope has settled
- These pictures will show whether the organ contains an abnormal mass
- Your child will not be radioactive during or after the procedure
- There are usually no restrictions before or after the test
- The procedure takes approximately 45 minutes to 1 hour
- A sedative may be used to help your child remain still and decrease anxiety
- Pregnant persons are not usually in the scan room and are not to hold patient in lap or change diapers for 12 hours



### **Ultrasound**

- Creates a moving picture of the inside of the body
- Uses painless ultrasound waves without risk to your child
- A clear gel and a transducer will be placed over the organ being examined
- The transducer will be moved around for about 10 minutes while the test is being performed
- Preparation depends on the organ being examined
- There are no restrictions after the test

### **X-rays**

- X-rays are used to take internal pictures of the bones and organs
- They can see size and shape, and can diagnose a possible infection, blockage or tumor
- If a problem is seen a more detailed picture may be taken
- Your child will be asked to remain still for a short period of time while a series of pictures is taken
- There are usually no restrictions before or after the test



## **Your Child's Treatment**

Standard treatment for most forms of cancer may include one or more of the following: surgery, radiation therapy and/or chemotherapy. We will let you know which of these is recommended to treat your child's disease.



### **Surgery**

There are different types of surgery.

- biopsy - a sample of tissue is taken from the mass or bone marrow to be evaluated
- resection - a large amount or the entire mass is removed.

### **Radiation Therapy**

- Radiation therapy is used to treat cancers in areas of the body not easily operated on, to shrink large tumors, and to destroy remaining cancer cells after a tumor is removed by surgery.
- High energy rays or particles are used to kill cancer cells, or keep them from growing.
- Treatments take a few minutes to each area being radiated, and are painless.
- Patient responsibility, care during radiation therapy. Treatment side effects will be discussed in detail with the radiation oncology department before your child starts radiation therapy. Total time required for each treatment from the time of arrival in the department, undressing, receiving the treatment, and dressing to depart is usually less than 30 minutes.

### **Chemotherapy**

- A medicine used to stop the growth of cancer cells.
- There are many different types of chemotherapy that kill cancer cells in different ways. Your child may receive a combination of different chemotherapies.
- Chemotherapy may be given in the following ways:
  - **Orally or PO:** This requires your child to take pills or liquids (elixirs) by mouth.
  - **Subcutaneous or Sub Q:** This requires a small needle inserted just under your child's skin. This route is used infrequently.
  - **Intravenous or IV:** This requires the chemotherapy to be given directly into the vein. A central line may be placed in your child to receive IV chemotherapy. This remains in place throughout treatment.
  - **Intrathecal or IT:** This requires the chemotherapy to be given directly into the spine. This is explained in the Tests and Procedures section.

## **Recommendations for Safe Handling of Chemotherapy**

While there is no research to suggest that chemotherapy can be harmful to the health of caregivers, the following recommendations are meant to be guidelines to help reduce your exposure to chemotherapy. They are based on recommendations from the Occupational Safety and Health Administration (OSHA) and the National Institute for Occupational Safety and Health (NIOSH). If you have questions, please talk to your nurse, doctor, or pharmacist.

- **Chemotherapy medicines can be passed into body fluids, including vomit, urine, and stool. Chemotherapy and body fluids should be handled with special care while the patient is receiving chemotherapy and for at least 48 hours afterwards.**

**During & for the 48 hours after the your child receives chemotherapy, caregivers should:**

- Wear gloves when handling diapers, vomit basins, or any material containing urine, vomit, or stool.
  - Always wash hands with soap and water after removing gloves.
- If your child is in diapers, remember to change the diapers frequently to prevent the chemotherapy from irritating your child's skin.
- Flush body fluids in the toilet. Close the lid before flushing, and flush the toilet twice.
- Carry linens, towels, or cloth diapers containing chemotherapy or body fluids away from the body.
  - Wash these items by themselves using regular laundry soap and hot water. Rinse twice.
- Reusable items, such as buckets or bedpans, should be washed well with soap and water after each use. Wear gloves & dispose the rinse water in the toilet, lid down & flush, or thoroughly wash your sink out after cleaning these items.
- Place disposable items, such as diapers, paper towels, or gloves, in a sealed plastic bag, and throw away in the trash.
- Mattresses and pillows may be covered with plastic covers if body fluids are likely to soak through bedding.
- If using syringes and needles to give chemotherapy, place used syringes and needles in a needle box from your Home Care Company or an empty rigid plastic container such as detergent jug. When the containers are three-quarters full, seal them. Return the sealed needle box to the company who issued it. If using a rigid plastic detergent jug, seal it & dispose in your trash.
- If you are exposed to chemotherapy, do the following:
  - Skin
    - Take off clothing that has chemotherapy on it.
    - Wash the skin and surrounding area with soap and water for 5 minutes.
  - Eye(s)
    - Flush eye(s) with water without stopping for 15 minutes.
    - Call poison control immediately.
- Cleaning up a chemotherapy spill
  - **Wear gloves**
  - Use a Chemo spill kit, if your home care company provides one. If not, you may:
    - Place paper towels over spill area to contain it.
    - Carefully wipe up spill.
    - Using paper towels, wash area with soap and water and dry.
    - Place all of the used paper towels & then your gloves into a plastic bag, seal the bag, and then throw it into a trash bag for disposal.
    - Wash your hands thoroughly.
- For questions about chemotherapy spill or exposure:
  - Call the clinic nurse immediately or if after hours, notify the oncology physician on call.
  - Call Poison control at 1-800-222-1222

## **NEUTROPENIC PRECAUTIONS**

When your child is neutropenic, there are certain precautions that should be taken to avoid infections. It is a good idea to follow these precautions even when your child is not neutropenic. It is however **extremely important** to practice them when your child is neutropenic.

- **Good hand washing:** Good hand washing is probably the single most important, effective way to prevent infection. Remind your child to wash his/her hands before and after going to the bathroom, after blowing their nose, before eating meals, after playing outdoors, and after playing with other children and/or animals.
- **Avoidance:** If at all possible avoid exposures to large crowds (especially in closed quarters), and people who have signs of infections such as fever, sneezes, sore throats, rash, vomiting or diarrhea. If other members of the household are ill, it is not necessary to separate parents and siblings. Just remember not to share drinks or food with each other, and to always practice good hand washing!! Check with your child's doctor or clinic nurse to see if your child should attend school/day care.
- **Hygiene:** Immunosuppressed patients (such as your child with neutropenia) are more susceptible to infection from normal flora (the little "bugs" that we all have inside and outside of our bodies and live with every day). Good Hygiene is very important (see Tips to Minimize the Risk of Infection).
- **Diet:** Wash all raw fruits and vegetables thoroughly (avoid any fruit with visible mold), avoid unpasteurized fruit juices and milk or milk products including cheeses and yogurt, avoid all raw or undercooked meats, fish, shellfish, poultry, game, eggs, hot dogs, sausage, and bacon
- **Implanted catheters:** If your child has an implanted catheter (Broviac, Port-A-Cath, or Hickman), its insertion site and/or line(s) could be a site for infection. Remember, **good hand washing before catheter care is extremely important!!!**

## **TIPS TO MINIMIZE THE RISK OF INFECTION**

- **Hygiene**
  - Hand-washing, Hand-washing, HAND-WASHING—for everyone!! Use paper towels. (Alcohol gel/foam cleansers are GREAT—keep one in a purse or the car for when you are out & about). Give your child his own set of towels & facecloths—launder frequently)
  - Good oral hygiene—brush at least 2 to 3 times daily with a soft tooth brush. Rinse and spit after any vomiting—wait an hour or so to brush; this allows nausea to subside & reduces loss of tooth enamel.
  - Have your child bathe or shower daily. (If your child has a Broviac or external central venous catheter, your child must wait about 3 weeks to shower in order for the site to heal. Once wet, the dressing must be changed as a sterile procedure. If you are not prepared to change the dressing DO NOT let it get wet.)
  - Clean rectum with wet wipes or wet washcloth after a bowel movement



## • **House Cleaning—Keep a clean house...**

- Vacuum at least once a week— vacuuming can stir up dust, do not have your child present in the room you are vacuuming.
- Minimize dust—use a damp cloth or a product like Endues on the dust cloth; do not have your child present in the room you are dusting. Do Not Use a feather duster.
- Clean ceiling fans weekly with a damp cloth.
- Change your A/C – heater filters every 3-4 weeks.
- Minimize mold & mildew in damp areas—bathrooms & around window frames. Use a bleach solution or products designed to eliminate mold & mildew to clean these areas. Clean frequently.
- Change your child's bed linens at least weekly and more often if necessary.
- Minimize house plants & avoid cut flowers in your home. Do not place any in your child's room.

## • **Pets**

- Keep your pets healthy. Sick animals can sometimes spread diseases to people. Have them see a Vet if they are ill.
- Keep your animals clean and free from fleas and ticks.
- Dogs are fine, but do not let them lick your child's hands or face.
- Indoor cats are fine, but litter boxes should not be near food or in your child's room.
- Cats that go outdoors (and indoors) have an increased risk of picking up a disease. It is very important to have your outdoor cats treated if they are ill.
- Do not let animals sleep in your child's room.
- Birds, Gerbils, hamsters, are fine if healthy—your child should not handle their food or feces or clean any cages.
- Fish are fine—but your child should not clean the tank. If you fish for sport with your child, your child should not bait the hook or remove the fish from the hook.
- No chicks, ducks, exotic pets, or reptiles---snakes, turtles, iguanas, etc.—they frequently carry Salmonella and other diseases.
- Have your child wash his or her hands after petting/playing with an animal.

## • **Food Preparation**

- Encourage your child to eat healthy foods.
- No uncooked meats and raw fish. Cook meats thoroughly.

- Wash raw fruits and vegetables thoroughly—twice. (Transplant patients and those who are severely neutropenic should cook vegetables and avoid fruits that are difficult to clean like strawberries or raspberries. Instead, choose fruits with a skin that can be peeled—like bananas or oranges.
- Juice and Dairy products (milk and yogurt) should be homogenized and pasteurized—avoid raw products.
- Do not allow your child to eat prepared foods or dairy products that have been sitting out unrefrigerated for over an hour.
- If you eat out, avoid cafeteria style restaurants, salad bars, and the “drive up”. Ask that your child’s food be freshly prepared.

#### • **General Information**

- Your child should not dig/play in soil in your yard/garden.
- A sandbox is fine for play as long as it can be covered when not in use. Outdoor animals frequently use a sandbox as a litter box—covering prevents this from occurring.
- No smoking in the home or car, particularly in the presence of your child. Tobacco smoke can be a chemical irritant and can predispose your child to upper respiratory infections. If you must smoke, please do so outdoors and wash up thoroughly before caring for your child.

#### • **AML, Aplastic Anemia, Relapsed ALL, & Bone Marrow Transplant Patients**

- These children are at greater risk for infection because of prolonged and severe neutropenia and therefore we must be increasing cautious in order to minimize this risk—good hygiene and cleanliness is very important—Don’t Forget...HAND-WASHING.
- These children **should wear special high filtering masks over their nose and mouth** when outside of their home or while outside of their room during hospitalization.
- We recommend the use of a portable HEPA air filtering unit in your child’s bedroom (or the room where he/she sleeps or spends the most time). The door to the room should be kept closed for these units to work effectively.

### **WHAT TO DO FOR BLEEDING**

- **Nosebleeds:** Keep your child in a sitting position. Instruct your child to breathe through the mouth. Apply pressure by gently, but firmly, pinching the nostrils closed across the bridge of the nose. Continue this pressure for 10 minutes. If the bleeding still does not stop, call the clinic. Once the nosebleed has stopped, do not allow your child to sniff hard, blow the nose or pick at the nose.
- **Bleeding of the gums or mouth:** If the bleeding is in an area that is easy to reach, apply gentle pressure until bleeding stops. If you cannot apply pressure, have your child hold ice water in his/her mouth until the bleeding stops.
- **A cut that does not stop bleeding on its own:** With a clean dry cloth hold gentle but firm pressure over the cut for at least 10 minutes. If possible, lift the body part that is injured above the level of the

heart. If the bleeding continues, call the clinic. If a cut is deep and the blood seems to be coming in spurts, apply pressure by pressing a cloth over the cut and take your child to the hospital at once.

- **Bleeding under the skin that is spreading or swelling:** Hold firm but gentle pressure with a soft cloth or an ice pack over the area for at least 10 minutes. Lift the area (such as an arm) above the level of the heart if possible. If the bleeding does not stop, call the clinic.
- **Sudden, severe headache or collapse:** This could be caused by bleeding inside the head. This is rare, but if it occurs, you should keep your child in a sitting position and bring him/her to the hospital at once, probably by ambulance (call 911).

## **TRANSFUSIONS**

A transfusion is defined as the injection of blood from one person into the blood vessels of another.

### **TRANSFUSION-RELATED INFECTIONS**

Blood products today are screened for the presence of HIV infection (AIDS) and other viruses such as Hepatitis, EBV, CMV, Malaria and Toxoplasmosis. The risk of infection through a transfusion is small. Talk to your doctor or nurse about any concerns you have about blood transfusions.

### **THE TRANSFUSION**

The amount of blood your child will receive depends upon his/her weight. You will be asked to sign a consent prior to your child receiving either a blood or platelet transfusion.

Your child will be closely watched during the transfusion. Expect the nurse to check the temperature, pulse, respirations, and blood pressure before, after, and sometime during the transfusion. A blood transfusion will require two to four hours to complete; platelets require 30 to 60 minutes to infuse, but may take longer. Transfusions can be done in the clinic or at the hospital.

**All transfusions must be irradiated.**

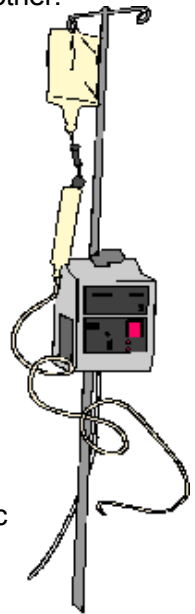
### **TRANSFUSION REACTIONS**

Transfusion reactions occur in 5% to 7% of all transfusion recipients. Reactions occur most commonly in patients who receive transfusions often. Common blood product reactions include:

- **Temperature:** Symptoms include a 2 - 3 degree increase, occasional shaking, chills, and rarely, nausea and vomiting.
- **Allergic Reaction:** Symptoms include hives, itching, wheezing, decreased blood pressure and possible, severe allergic reaction (anaphylaxis or shock).

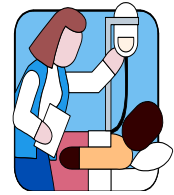
If at any time you are concerned that your child is experiencing a reaction, alert your nurse so that your child can be checked and proper action taken.

**\*Please call The Blood Alliance (904-353-8263 / 1-888-447-1479)  
if you would like to learn of their Recipient Benefits Program\***



## **Hospitalization and Infection**

If your child should develop a fever or other sign of infection while his/her blood counts are low, it may be necessary for him/her to be admitted to the hospital for IV antibiotics.



When hospitalization is required, the usual sequence of events can include:

- Blood cultures are obtained. Throat, urine, any mouth lesions or draining sores may also be sampled to see if bacteria are present in your child's blood.
- IV antibiotics are started within one hour of admission. Results from cultures may not be known for 24-48 hours. Because the source of infection may be hard to identify, antibiotics are chosen to cover the most likely and most serious sources of infections.
- Your child will be allowed to go to the playroom during special hours if he/she feels up to it. Your child will not be placed in isolation unless the child has a contagious disease (for example - chicken pox).

## **Contagious Diseases**

### **Fever**

- A fever may indicate an infection.
- Any time your child does not feel or look well, take his/her temperature. **If he/she has a fever of 101 or more, call the clinic or doctor immediately. Do not give your child Tylenol, Advil, or Motrin until you speak with the clinic nurse or doctor.**

### **Chicken Pox**

- Chicken pox, caused by the varicella virus, is a contagious disease usually associated with children. For most children it is usually mild and serious problems are rare. It can be life threatening for the immunosuppressed child.
- Chicken Pox are lesions that look like blisters. The time period between when the child is exposed and when the pox are first seen, called the incubation periods, ranges from 10-21 days.
- Children are considered "contagious" 24-48 hours before the lesions start until all the lesions are all dried up. The disease can not be passed to others when all the blisters are dried and the scabs begin to fall off.
- Children are immune (cannot catch the disease again) to chicken pox once they have had the disease. If your child has received the varicella vaccine, they can still get chicken pox.
- If your child is considered susceptible to chicken pox, and has an exposure to chicken pox, the doctor needs to be notified. The child who has never had chicken pox or the vaccine, will need to receive Immune Globulin as soon as possible after the exposure. This medication is given as an infusion.
- If your child develops chicken pox, he/she will be given a medication called acyclovir. This medicine helps control the infection and reduces the risk of serious problems. Your child will most likely be hospitalized for 24-48 hours.
- The fear of chicken pox should not keep your child out of school or away from other children. Friends and school personnel should be informed to notify you in the event of possible exposure.
- During cancer treatment, the signs of Varicella infection can be different from the usual infection. If your child develops any suspicious rashes or signs, call the doctor.
- Call the clinic/hospital **before you come** if you think your child has chicken pox. This is important so other patients and children in the waiting rooms will not be exposed.

## **Shingles**

- Shingles is a reoccurrence of the varicella virus.
- Shingles occur in people who already have had chicken pox.
- If you've never had chicken pox and are exposed to someone with shingles, you can develop a chicken pox infection.
- Call the clinic/hospital **before you come** if you think your child has shingles. This is important so other patients and children in the waiting rooms will not be exposed.

## **GENERAL INFORMATION**

### **Immunizations/Vaccinations**

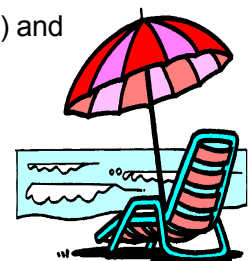
- Because chemotherapy lowers the ability of the immune system to fight infections, immunizations (also called vaccinations) should not be given for the entire length of treatment.
- Your child can receive any missed vaccines at the completion of treatment.
- Family members should only receive "killed" or inactivated virus as an immunization when your child is on treatment.
- Inform your clinic nurse when it is time for brothers, sisters or playmates to have their scheduled immunizations.
- All family members need a yearly flu vaccine. For more information ask your nurse.

### **Hair loss (alopecia)**

- Many of the chemotherapy drugs cause hair loss.
- For the very young child this will probably be of no concern to them. To the parents and older children, especially adolescents, hair loss can be traumatic.
- Patterns of hair loss differ. Some children seem to lose their hair overnight, while others will lose it over a period of days or weeks. Sometimes there is very little hair loss.
- In whatever way your child experiences hair loss, it is most important that he/she be told beforehand that this is a possibility. The child needs also to be told their hair will grow back, although it may be a different color and texture.
- It is not altogether unusual for a child to re-grow a full head of hair while still on treatment and/or lose it more than once.
- There are several possibilities for head coverings. Some children prefer to wear a hat, scarf or bandanna. If needed, the physician can write a note to allow your child to wear a hat or scarf to school.
- For the child who chooses to wear a wig, it is best to shop around before hair loss becomes very noticeable. That way hair color and style can be copied. Boys, as well as girls, may want to wear wigs.
- A bare head loses heat in the winter and gets sunburned in the summer. Encourage your child to use proper head protection in the form of a hat, wig, or scarf or sunscreen when outside.

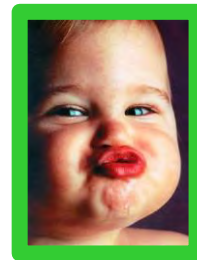
### **Sun Exposure**

- **Radiation and certain chemotherapy medicines will make your child more sensitive to the sun**, so he/she may sunburn easily and should be protected from exposure.
- Be aware of the time spent in the sun: wearing protective clothing (especially hats) and use a **SPF 45 or higher** sunscreen lotion.



Treatment for cancer causes changes in the mouth. The chance of tooth decay/cavities, mouth sores and infection in the mouth is increased when being treated for cancer. Extra attention to daily cleaning to keep your child's mouth clean is important. The lining of the mouth (mucous membrane) protects the inside of the mouth against infection. Mouth sores or "mucositis" may develop when your child's blood counts are low, resulting in pain, not eating, fever, and blood stream infections. Your child may have a dry mouth and lips. To help decrease or prevent mucositis there are things you can do to help your child, both while in the hospital and at home.

## Brush, rinse, lip care



- Gently brush your child's teeth 2 times each day (after every meal recommended)
  - Use a soft toothbrush and mild toothpaste
  - A cotton swab or foam brush should be used in babies who have no teeth
  - Use a foam brush ("toothette") or gauze if the gums/mouth are tender or bleeding
  - Change toothbrush at least every 3 months and after any infection
- Swish and spit 3 times a day (after every meal)
  - Avoid alcohol based mouthrinses—check with your nurse for good choices
  - Salt water works well-1/2 teaspoon baking soda, 1/4 teaspoon salt mixed in 1 cup warm water
  - Your doctor may prescribe a special mouth wash to help decrease pain if your child does have painful mouth sores
- Lip care 2 times or more each day
  - Non-petroleum based products—examples include Burt's Bee lip balm and EOS organic
  - No sharing of lip care products
- Eating cold things such as ice, popsicles, slushies while your child is getting certain chemotherapy IV infusions may prevent or decrease mouth sores. Ask your nurse if this will help for your child

Children's Hospitals' Solutions for Patient Safety (SPS CLABSI Workgroup, Hem/Onc). Dec.16, 2016.  
OCHSPS <[OCHSPS@cchmc.org](mailto:OCHSPS@cchmc.org)>

Ped-Onc Resource Center. Mouth and Teeth: care and Problems. Last modified 12/01/2014  
<http://www.ped-onc.org/treatment/mouthcare.html>



### **Dental care and oral hygiene**

- Good mouth care during chemotherapy is important
- Because immunosuppressed patients have an increased susceptibility to infection from normal mouth bacteria, patients are to receive oral hygiene at least 2-3 times a day with a **soft** toothbrush.
- If your child has a low platelet count, and his/her gums bleed while brushing, switch to a soft sponge (toothette brush) to clean his/her teeth.
- Dental care remains an important part of care. Please check with your child's nurse or doctor before scheduling any dental appointment.

### **School**

School is an important part of a child's life. It is their work, their social life and it paves the way for their future. For these important reasons it is a concern for parents and a challenge for hospital staff to keep the connection between the child and the school open and active. Because school is a basic part of your child's life it is important that, whenever possible, your child return to the school he/she would normally attend.



- Nemours Children's Specialty Care offers a program to help the patient going back to school after diagnosis or when entering a new grade level. Its focus is on the particular issues concerning re-entering the school setting, with emphasis on the emotional impact of cancer on the child and his/her peers. Administration, guidance counselors and other interested staff are invited to attend the presentation. Pre-school age through high school have the option to request a visit. Please contact the clinic child life specialist for further information.
- The doctor will let you know when he thinks your child should return to school. See your social worker or school guidance counselor regarding the homebound education program. This is usually available through the public school system. Once you return home, your child may need to continue with homebound services.

### **Sports**

- Your child may participate in sports when approved by the doctor.
- If your child has a low platelet count, he/she should avoid contact sports (football, Karate, etc.) or rough play (skateboarding, surfing, trampolines, ATVs) that could cause physical injury, especially to the head.



### **Swimming**

**No fresh water swimming** (lakes, creeks, ponds, rivers) is permitted due to bacteria & algae counts.

If your child has not had a bone marrow transplant, they may swim in a well chlorinated pool anytime. If they have a Broviac, the dressing must be changed immediately after swimming. Your child can swim in the ocean if their **ANC is over 500** and they don't have a Broviac.

If your child has had a bone marrow transplant, they may swim in a well chlorinated pool if they are past day 100. To swim in the ocean, it should be more than one year since their allogeneic transplant and they should be off all immunosuppression. Children having autologous transplants may swim in the ocean six months after transplant.

*How to reduce the risk of swimming related infections:*

1. Don't allow your child to swim if they have diarrhea
2. Take your child for bathroom breaks often and before they say they need to go
3. Change diapers in the bathroom and not at poolside.
4. Wash your child thoroughly – especially the rear end-with soap and water before swimming
5. Wash hands with soap and water after using the toilet or changing diapers.
6. Teach your child not to swallow pool water.

## **PAIN MANAGEMENT**

Learning to cope with pain more effectively can reduce discomfort and help your child gain feelings of control. Review the ideas presented below to determine what will work best for your situation. In general, materials and techniques that quickly capture your child's attention are likely to work best.

- ***DISTRACTION*** - Focus on something other than the pain. If a procedure is scheduled, remember that some children want to watch what is happening. Do not pressure them to look away as this may increase anxiety.

### ***Magic wands***

Musical Storybooks or Pop-Up Books

"Where's Waldo", "I Spy" or other hidden picture books

Favorite music or soothing music; with or without a headset

Hand-held video games

Sing a song, recite the alphabet, or spell word games

Count until ready for the procedure to begin; count how long the

Procedure takes; count as high as you can just for the fun of it!



- ***BREATHING***: Deep breathing promotes relaxation which may decrease heart rate, blood pressure and muscle tension.

Blow bubbles, a pinwheel, a feather or a party blower

Gentle blowing to blow pain away or to help hold veins open

Deep breathing: breathe in slowly and deeply. Breathe out letting go

Of tension or scary feelings with each breath

- ***IMAGERY***: Encourage child to imagine pleasant places or events. There are also guided imagery cassettes available.

Think about something nice like a favorite place, activity, friend, super hero or story.

Guide your child through how it feels, who is there, what they are doing, etc.

Help your child to see it.

Your child needs to focus and relax, so talk in a slow, calm voice and try not to talk excessively. Pictures may be helpful.

Child's eyes may be open or closed.

- ***MORE IDEAS:***

Positive Talk: "I can do it" "You can do it"

Have someone present for comfort.

Squeeze someone's hand or a soft ball.

Soothing touches: gentle stroking of arm, leg, hand or head.

Sit on someone's lap and gently rock while singing or talking softly.

Watch procedure or turn head away and don't watch.

CRY



## **Anesthesia/Sedation for Procedures**

Procedures such as spinal taps, bone marrow aspirations and bone marrow biopsies are anxiety producing and painful for children. Depending on your child's diagnosis, the number, frequency, and type of procedure will vary. For all of these procedures there are three types of sedation possibilities.

### TYPES:

1. Local anesthesia with sedation given by Oncologists
2. Local anesthesia with sedation given by Anesthesiologists
3. General anesthesia given by Anesthesiologists

### RISKS/BENEFITS of #1 & #2 Include, but are not limited to:

- Does not lose airway reflexes
- Aware and responsive, but sleepy
- May not be able to hold still for procedure to be safely performed
- With any sedation, patient may stop breathing and require assistance by physician
- May not have amnesia for procedure

### RISKS/BENEFITS of #3 Include, but are not limited to:

- Patient has amnesia for procedure
- Loss of airway reflexes with potential for vomiting and aspiration into the lungs causing pneumonia
- Laryngospasm – the closing of the vocal cords, making it difficult to ventilate the patient. It may be necessary to give intravenous (IV) medications or to place a breathing tube temporarily to correct.

Conditions may arise or be present in which the Anesthesiologist may feel that it is not safe to administer general anesthesia. These will be evaluated on a case-by-case basis.

*The following conditions must be met by patients prior to receiving general anesthesia.*

1. Nothing to eat or drink after midnight (includes gum).
2. No active cold or upper respiratory infection.

## **FAMILY ISSUES**

**HOW DO I TELL MY CHILD?** The amount of information and the approach used in telling your child what is happening depends on your child's age and their level of maturity. Regardless of what approach you use, all the communication should be honest and the correct words should also be used when making reference to individual items. It is important to remember that you know your child the best. The staff at the treatment center is available to tell your child their diagnosis, but only if you feel that you can't and/or need help in doing so. When telling your child, remember to emphasize the treatment available so your child knows that something will be done to help him/her get better.

- **Infancy to 2 years of age:** The main concerns that children at this age have is being separated from their parents and controlling their environment. You will usually see that these children are often frightened by all medical procedures and tests. The children will move, scream and cry in an attempt to control what is happening to them.

After 15 months, children will become more curious about what is going on. Honesty always is the best policy. You should never tell your child that they are not going to the hospital when they are, and don't tell them that something is not going to hurt when it will. As the child gets a little older, you can begin to give them some control by having them participate in some aspects of their treatment, such as what kind of juice they want to take with their medicine or where they might want their IV taped.

- **2-7 Year Olds:** Children at these ages begin to understand their illness better, but they still believe that everything centers around them. They expect to see results immediately. They go to the hospital and expect to go home right away regardless of how long it will be necessary to be hospitalized. Children often see their illness as something they did wrong. They may feel that they are being punished because of doing "something bad". It is important to remind the children that everything being done for them is to help them feel better.
- **7-12 Years of Age:** Children during this age are beginning to understand the relationship between cause and effect. They acknowledge that something is wrong, and their "symptoms" are the clue that something is not right. They tend to cooperate with treatment. When you tell your child their diagnosis, they can understand more details. You can use the word cancer and tumor with a supportive tone of voice to prevent any fear that they might be imagining.
- **Teenagers:** Teenagers are able to understand explanations in scientific terms. Although teenagers continue to define illness by specific symptoms, they can also understand the reasons for these symptoms. You can explain cancer as a "disease" in which a few cells in the body have divided and multiplied out of the normal controlled cell division. The cells are growing faster than they should. The cells cannot perform their normal function and therefore, he/she may feel ill. Our goal of treatment is to make all the cells work properly. We need to rid the body of these rapidly dividing cells.



**Brothers and Sisters:** Brothers and sisters are often confused and overwhelmed with what is going on regarding their brother or sister's illness. Just as we talked about the importance of honest communication with the sick child, it is equally important with your other children. It is imperative to correct any myths that they might have such as, "Am I going to catch it also?" "Is my brother sick because I said something bad to him?"

- Brothers and sisters can develop problems coping with cancer too. It may be difficult for them to concentrate in school because they worry about their parents, brothers, or sisters. The sibling might experience these problems in an attempt to gain the same attention that their brother or sister is receiving from the parents. At times siblings also can become preoccupied with thoughts about death. It is important that you are honest with your children and allow them an opportunity to talk about their feelings. The child needs to be reassured that they didn't cause their siblings illness by having bad thoughts about them.
- Children need to feel that despite the family stress, their role within the family has not changed. Although you will be very busy with your child's treatment regimen, it is important for you to spend private time with your other children. The child's brother or sister will also have an opportunity to feel that their needs are significant and they will not feel left out.
- Siblings often have fearful thoughts about their brother or sister's treatment routine. They are afraid of what goes on when they stay over night in the hospital, particularly when the hospitalizations are for long periods of time. Discuss with the clinic staff whether your other children can come for clinic visits, and whether they can have special visiting privileges in the hospital.
- Make their teachers aware of the sibling's illness. Sometimes, it is difficult for a sibling to keep up in school due to his/her concerns about what is happening with his/her brother or sister.

### **Discipline**

- **Treating your child as normally as possible is very important.** You should feel comfortable in maintaining control. This includes having your child listen to you regarding what is considered acceptable behavior.
- Medication often makes your child feel angry, irritable, and moody. Discipline is difficult because your child's behavior is often an indication of their frustration, anger, and/or sadness. These feelings of anger and sadness may not come up until your child's hospitalization is over. When children return home, they miss the structure and organization that was there before they got sick. Children knew what their limitations were and what behaviors were inappropriate. We're aware that your entire family routine has been disrupted. Your child needs to now find new limits and they will test their parents and family members to receive reassurance that limits will be established again.
- When you are figuring out the best approach, consider the following:
  - ❖ What should be expected of your child given their illness and possible treatment effects?
  - ❖ Remember the approaches you used before your child got sick. What were their capabilities at that time? Have they changed?
  - ❖ As much as possible, you should maintain visual discipline practices. Being overly permissive may confuse your child and complicate his/her adjustment to treatment rather than helping it.

## **HOSPITALIZED CHILDREN**

Hospitalization often results in increased anxiety and interruptions of normal growth and development. Children may exhibit a variety of reactions to hospitalization including:

### **Overt or Active Responses**

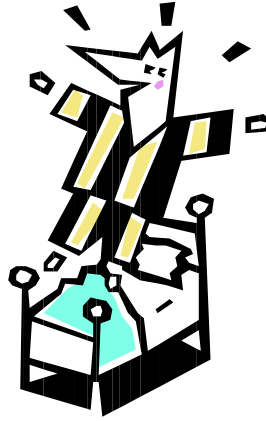
- Crying, whining, or screaming.
- Clinging.
- Resisting medication/treatment.
- Being self-destructive.
- Being destructive of environment.
- Fighting.

### **Passive Responses**

- Excessive sleeping.
- Decreased communication.
- Decreased activity.
- Decreased eating.

### **Regressive Behavior**

- Alterations in sleep patterns.
- Being tense, anxious, or restless.
- Manifesting fears.
- Being overly concerned with one's body.
- Displaying compulsive behavior.
- Stop walking, bed wetting, wanting bottle/pacifiers.



The following are a few key points that will minimize these potentially negative consequences related to hospitalization.

### **INFANTS**

- Provide consistency of care as much as possible to enhance security and trust.
- Provide relief from physical tensions through sucking and /or being rocked.
- Attempt to maintain eating and sleeping routines from home.
- Continue to provide stimulation through age appropriate toys.

### **TODDLER**

- Toddlers are extremely bothered by separation seeing it as abandonment and as a result may become anxious, withdrawn, or hyper.
- Provide familiar routines and rituals from home to normalize the hospital environment.
- Provide opportunities for independence and choices to decrease feelings of frustration.
- Provide consistent structure and limits despite illness.
- Hospitalization may result in temporary loss of potty training skills. It is important to realize this is normal rather than punishing your child.

## **PRESCHOOL**

- Give your child the opportunity to continue using pretend play (with puppets, etc.) Children often show their fears or misunderstanding during play.
- Provide opportunities for choice whenever possible ("Do you want to take your medicine with juice or water?") to increase a sense of control in your child.
- Provide explanations for procedures in extremely concrete words and be aware of words which may be misunderstood ("dye"=die, "I.V."=ivy).
- Preschoolers often view hospitalization and illnesses as punishment and they may feel guilty. They need constant reassurance that they are not to blame.
- Provide consistent structure and limit setting despite illness.

## **SCHOOL-AGE**

- This age group may sometimes feel inferior. Therefore, it is important to focus on what your child can do and give opportunities for control and success.
- They may show a lot of tension through sleeping, elimination problems, or other physical behaviors such as lip licking.
- Can now understand cause and effect but explanations still need to be kept concrete.
- The fear of pain is heightened therefore discuss coping and pain management.
- Need opportunities for socialization and to practice school skills.
- Continue your home routines and schedules as much as possible (for example, meal times, bath times) at home and in the hospital.

## **ADOLESCENTS**

- Be respectful for their need for privacy (keep door closed).
- Peers are an extremely important part of an adolescent's life; therefore, they need opportunities for socialization and encouragement to maintain contact with their friends outside the hospital through phone calls, visits, or letter writing.
- VERY concerned with body image and appearance and this may result in lowered self-esteem, depression, etc.
- Can handle and need more complex explanations of procedures and illness, since adolescents now display abstract thinking.
- To increase compliance it is important to give them opportunities for choices and control whenever possible.
- Their desire for independence may mean they need time alone.
- Encourage self-care to increase opportunities for independence.
- This is the age of risk taking, impulsive thinking, and feelings of invincibility.
- Adolescents are concerned with the future and how their illness may affect that. They have more difficulty admitting their fears. Encourage opportunities for discussion or self-expression.

## **TAKING CARE OF YOURSELF**

### **It's Always Unexpected**

Cancer comes without warning. Existing problems are increased and new ones are created. Increased anxiety, financial concerns and less time for work and fun are common examples of the difficulties families face. Most families will quickly ask "Why us?" or "Why our child?" Personal feelings become stronger and it is natural for families to feel many emotions. These emotions are a normal response to a crisis.

### **Be Patient With Yourself**

Caring for a child with a chronic illness while trying to maintain a normal life is a challenge for all parents. Trying to cope with a childhood cancer and the many emotions you experience can create stress. There is no right or wrong way for parents to support themselves through the experience. The following are some ideas which may help you in the days ahead:

- When you feel numb and overwhelmed it is important to try to give yourself time to understand what is happening. It may take weeks to fully understand the meaning of what you have been told. It may take months to incorporate this new information into your family life and routines.
- Sort out the medical facts given by your child's doctors. Recognize the difference between them and the stories offered by relatives, friends and neighbors.
- Be aware of your feelings. Talking about them may help.
- Keep notes for yourself. There may be times when you feel unable to listen or remember things. It can be frustrating when you are trying to recall what you have been told about your child's treatment, drugs, and possible side effects.
- Ask questions of the health care team. It may be helpful to write down questions you want to ask the team.
- Take care of yourself. Your health and well being influence your ability to care for your child.
- Learn to utilize many resources. Accept offers of support. Friends, neighbors and family may be able to provide valuable assistance during this time. Remember, by accepting their offers, it allows them to feel like they were able to lighten your burden.
- Give yourself time to develop your own style of coping. Learn to take one day at a time. Set priorities for what must be done rather than becoming overwhelmed with unnecessary tasks.
- Do not expect too much from yourself.



# Other kids with cancer say:

## Advice From Other Patients



- Be nice to your kids, but don't be too easy.
- Sometimes kids don't want to tell their parents how they feel about their treatment. It might be easier to talk to a friend or someone at the hospital or at school.
- Brothers and sisters can feel left out. They need a lot of attention too.
- Treat me the same. I am the same kid. I just have cancer.
- It can be rough, but you can learn a lot. You will make it.
- Have hope.
- ***It gets easier.***

# **NUTRITION**

## **WHY IS NUTRITION IMPORTANT?**

- Eating a balanced diet can help improve strength and prevent a delay in growth.
- The risk of infection decreases and immune function increases when children are well nourished.
- Children who are in good nutritional shape are better able to handle the side effects of cancer treatment.

## **WHAT DOES EATING WELL MEAN?**

- The rule of thumb: eat a variety of different foods every day.
- No one food group contains all of the nutrients needed. A diet should include daily servings from the following food groups:



<b>Grains:</b>	The grains, such as bread, pasta, rice, and cereals provide a variety of carbohydrates and B vitamins. Carbohydrates provide an excellent source of energy, which the body needs to function well.
<b>Dairy Foods:</b>	Milk and other dairy products (yogurt) provide protein and are the best source of calcium.
<b>Protein:</b>	Meat, fish, poultry, eggs, peanut butter and legumes (beans) give you protein, as well as many vitamins and minerals.
<b>Fruits and Vegetables:</b>	Raw or cooked vegetables, fruits and fruit juices provide certain vitamins (such as, vitamins A and C) and minerals the body needs.

## **NUTRIENTS AND FOODS**

- Foods High in Phosphorous

<b>Dairy</b>	Cheese, cottage cheese, cream cheese, ice cream, milk, milkshakes, pudding, yogurt.
<b>Meats</b>	Eggs, flounder, gizzards, liver, salmon, scallops.
<b>Fruit</b>	Blackberries
<b>Starches, Cereals, &amp; Breads</b>	Bran, Cheerios, cornbread, muffins, oatmeal, pancakes, Shredded Wheat, waffles, whole wheat bread.
<b>Vegetables</b>	Asparagus, broccoli, Brussels sprouts, corn, mushrooms.
<b>Miscellaneous</b>	Any dark-colored soft drinks (like Coke, Pepsi, Dr. Pepper, Tab, Root Beer, etc.), molasses, orange soda, peanut butter, strawberry soda.



- Foods High in Potassium

**Breads/Cereals**

All Bran, any cereal with dried fruit, Boston Brown Bread, Bran Chex, Captain Crunch, Grapenuts, Fiber One, Fruit & Fibre, Life, Mueslix, Oat Bran, Oat Flakes, 100% Bran, Pumpernickel, Raisin Bran, Total, Wheat Chex, Wheat Germ, Wheaties.



**Fruits**

Banana, cantaloupe, currants, dried fruits, honeydew, mango, orange, orange juice, papaya, prune juice, tangelo, tangerine, juice, kiwi, watermelon.

**Vegetables**

Avocado, bamboo shoots, brussels sprouts, carrots (raw), chicory, \*dried beans, \*dried peas, greens (any type), leeks, mushrooms, parsnips, peppers (hot), , pickles, \*\*potatoes, spinach, \*\*\*squash (winter), succotash, sweet potato, tomato juice, tomato paste or puree, tomatoes, V-8 juice, yams.

**Miscellaneous**

Brown sugar, milk, molasses, nuts, yogurt.

- \* This includes baked beans, black beans, black-eyed peas, butter beans, chickpeas, chili with beans, cowpeas, field peas, garbanzo beans, great northern beans, kidney beans, lentils, lima beans, navy beans, pork-n-beans, red beans, split peas, soups with beans or peas, and white beans.
- \*\* This includes baked potatoes, french fries, hash browns, instant potatoes, mashed potatoes, potato chips, potato salad, potato soup, potato sticks, and scalloped potatoes.
- \*\*\* This includes acorn, butternut, rhubarb, and spaghetti squashes.

- Foods High in Magnesium

**Cereal/Grains**

All Bran, Bran Buds, Cheerios, Fiber One, Fruit & Fiber, Oatmeal (instant only), 100% bran, Raisin Bran, Roman Meal (cooked), whole wheat natural cereal (cooked)

**Legumes**

Dried beans (cooked), dried peas (cooked), soybeans (whole: roasted, baked, boiled, etc.)

**Nuts and Seeds**

Almonds, mixed nuts, peanut butter, pumpkin seeds

**Vegetables**

Avocado, spinach

# **MANAGING EATING DIFFICULTIES DURING TREATMENT**

## **DIARRHEA:**

Possible causes: radiation, chemotherapy, some antibiotics, gastrointestinal Graft vs. Host Disease, intestinal infections, oral medications such as magnesium salts, metoclopramide, Reglan D, lactose intolerance.

### ***Do Eat***

- Smaller amounts of food at each meal.
- Food and beverages high in potassium and low in fiber such as ripe bananas, potatoes without the skin, tomato juice, Gatorade® orange juice, peach and pear nectar, baked fish and chicken, ground beef, eggs, well cooked vegetables (excluding beans, broccoli, cauliflower and cabbage), canned fruit, rice and white bread.

### ***Do Drink***

- Increase your intake of fluids to prevent dehydration.
- Between meals, rather than with meals.
- Lactaid® treated dairy products or low-lactose milk and dairy products.

### ***Don't Eat***

- High fiber foods such as bran, whole grain cereals and bread, vegetables, fruits, popcorn, nuts and seeds.
- Rich gravies and sauces.
- Food and beverages such as tea, coffee, chocolate, colas and other caffeinated soft drinks.

## **CONSTIPATION:**

Possible causes: Narcotics, chemotherapy

### ***Do Eat***

- High fiber foods such as raw fruits and vegetables, whole wheat bread and cereals, dried fruit, dried peas and beans.

### ***Do Drink***

- Warm beverages
- Increase fluid intake.

### ***Over-the-Counter Options:***

- Miralax
- Senna

### ***Miscellaneous***

- Engage in light exercise.
- Ask your doctor about stool softeners or laxatives if the problem persists.
- Do not skimp on fluids when increasing your fiber intake.

## **WEIGHT GAIN:**

Possible causes: Steroids

### **DON'T EAT/OR REDUCE INTAKE OF**

Salt:	Don't add salt to food. Avoid foods that are high in salt such as:
Meats:	Bacon, bologna, cold cuts, chipped beef, corned beef, hot dogs, ham, salt pork, sausage, canned and salted meats.
Prepared Foods:	Bouillon, canned or frozen soups (most soups are fine), frozen dinners, olives, pickles, pizza.
Salted Snacks:	Potato chips, pretzels, corn chips, popcorn, etc.
Seasonings:	Salt, catsup, celery salt, onion salt, chili sauce, monosodium glutamate (MGS), mustard, soy sauce, steak sauces, and seasonings mixed with salt.
Vegetables:	Sauerkraut, beans, cooked with salt pork.

## **NAUSEA AND VOMITING:**

Possible Causes: Chemotherapy, radiation therapy, various medications, gastrointestinal GvHD, infection, mucous drainage from mouth and sinuses.

### ***Do Eat***

- Small frequent meals
- Dry crackers, toast, graham crackers.
- Cold foods, rather than warm foods, because they tend to have less food odor.
- Low fat foods such as cooked vegetables, canned fruit, baked skinless chicken, sherbet, fruit ice, pretzels, toast, crackers, vanilla wafers, and angel food cake.

### ***Do Drink***

- Clear cool beverages such as carbonated beverages, flavored gelatin, popsicles, and ice cubes made of a favorite liquid.
- Liquids slowly through a straw.
- Amounts of liquids frequently throughout the day.
- Request that food trays be brought to you without covers on the plates to avoid being overwhelmed by the smell.
- Request medications to control the nausea if it is severe.

### ***Don't Eat***

- Spicy foods.
- Overly sweet foods.
- Foods with strong odors or high fat, greasy foods.

### ***Don't Drink***

- A lot of liquids with meals or hot liquids.

### ***Miscellaneous***

- Don't lie flat on your back after eating. If you need rest, sit or recline with your head elevated.
- Don't go near cooking areas where smells might be offensive.

## **LACK OF APPETITE/WEIGHT LOSS:**

- Possible causes: radiation therapy, chemotherapy, infection, psychological issues such as depression and fatigue.
- Refer to: “Managing Your Child’s Eating Problems During Cancer Treatment”, National Institute of Health. \* See your dietitian for a copy of the book.

### ***Do Eat***

- Small, frequent, high-calorie meals.
- Dense, high-calorie foods such as cheese, whole milk, cream, whipped cream, sour cream, cottage cheese, ice cream, extra butter or powdered milk, eggs, oil, mayonnaise, peanut butter, wheat germ, nuts, instant breakfast beverages and fruits.
- Eating well is as important as some of your medications. It’s important that you keep trying to eat, even you don’t have much of an appetite.

### ***Do Drink***

- High-nutrient liquids such as juice or milk, instead of low-calorie drinks like coffee, tea or diet drinks.
- Use carbohydrate supplements such as Polycose®, protein powders such as Beneprotein® complete nutrition supplements such as Ensure®, Boost®, or Carnation Instant Breakfast®, provided they have been approved by your dietitian. Alternatively, nonfat dry milk powder can be added to casseroles, cooked cereals and mixed dishes.

### ***Miscellaneous***

- Create a pleasant, mealtime atmosphere, for example, colorful place settings, varied food colors and textures, soft music, enhancing food aromas.
- Engage in light exercise to stimulate your appetite.
- Address the psychological problem, if one exists, with the help of a psychologist or social worker.

## **CHANGES IN TASTE:**

Possible causes: radiation therapy, chemotherapy, some pain medications, some antibiotics

### ***Do Eat***

- Foods and beverages cold or at room temperature.
- Strongly flavored foods such as chocolate, lasagna, spaghetti or barbecued foods, unless you have mouth or throat sores.
- Tart or spicy foods, unless you have mouth or throat sores.
- Protein foods without strong odors, such as poultry, eggs, and dairy products rather than those with strong odors such as beef or fish.
- Meat with something sweet, such as cranberry sauce, jelly or applesauce.
- Some patients have trouble eating bland foods such as casseroles, custards, puddings, unsalted chips and crackers overcooked vegetables, plain meats and plain fish. Red meat, chocolate, coffee and tea may also be difficult to tolerate.
- Select food that smells appetizing.
- Add sauces to foods.
- Use plastic utensils if foods seem to have a metallic taste.

### ***Do Drink***

- Drink fluids with your meal to rinse away any bad taste.

## **THICK SALIVA:**

Possible causes: radiation therapy, dehydration

### ***Do Eat***

- Eat a lighter breakfast if you have mucous build up in the morning, and bigger meals in the afternoon and evening.
- Eat soft, tender foods such as cooked fish and chicken, eggs, noodles, thinned cereals, blenderized fruits and vegetables diluted to a very thin consistency.
- Eat small, frequent meals.
- Try sucking sugarless, sour lemon drops.

### ***Do Drink***

- Club soda (seltzer) or hot tea with lemon.
- Lots of fluids.
- Diluted juices, broth-based soups, and fruit flavored beverages such as Koolaid® or Hi-C®.

### ***Miscellaneous***

- Rinse frequently with a saline solution (1 quart water to ¾ tsp. salt, and 1 teaspoon to 1 tablespoon baking soda).
- Switch to a liquid diet if problem is severe.

### ***Don't Eat***

- Thick cream soups or nectars.

## **DRY MOUTH:**

Possible causes: radiation therapy, anti-nausea medications, antihistamines, chronic oral GvHD.

### ***Do***

- Add sauces, gravies, broth and dressings to foods.
- Suck ice chips, popsicles, gum or sugarless hard candies to keep the mouth moist.
- Try including citric acid in your diet to stimulate saliva production. Citric acid is present in oranges, orange juice, lemon, lemonade and sugarless lemon drops. You can also add lemon to tea, water and soda.
- Drink liquids with your meals.
- Practice good mouth care.
- Ask your dietitian or doctor about commercial saliva substitutes such as Salivart®, Mouth-Kote®, Saliva Substitute® and Xerolube®.

### ***Don't***

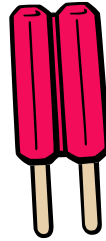
- Eat plain meats, bread products, crackers, or dry cake.
- Eat or drink very hot foods or beverages.

## **MOUTH AND THROAT SORES:**

Possible causes: radiation therapy, chemotherapy, and infections, Graft vs. Host Disease.

### ***Do Eat***

- Foods lukewarm or cold, rather than hot.
- High protein, high calorie foods to speed healing of the sores.
- Soft foods such as cream soups, cheeses, mashed potatoes, yogurt, eggs, custards, puddings, cooked cereals, ice cream, milk shakes and pasteurized eggnog. \*these foods are also high in calories and protein.
- Cold foods such as milk shakes, cottage cheese, yogurt, watermelon, gelatin and soft canned fruit (blenderized if necessary).
- Soft, non-irritating frozen foods such as popsicles, ice cream, frozen yogurt and slushes.
- Cook foods until tender or soft.



### ***Do Drink***

- Through a straw to bypass mouth sores.
- Fruit nectars and fruit flavored beverages instead of acidic juices
- Liquid or blenderized diet, or a complete nutrition supplement such as Pediasure®, Carnation Instant Breakfast®, or Boost®.

### ***Miscellaneous***

- Maintain good mouth care.
- Request pain medications if discomfort is severe.

### ***Don't Eat***

- Tart or acidic foods and beverages such as citrus fruits and juices and pineapple juice.
- Salty foods and drinks, including broth.
- Rough or coarse foods such as raw fruits and vegetables, dry toast, grainy cereal and breads, and crunchy snacks
- Extremely hot foods.
- Strong spices such as peppers, chili powder, nutmeg and cloves.

### ***Don't Drink***

- Alcoholic beverages
- Extremely hot beverages

## EXAMPLES OF HIGH CALORIE SNACKS/SUPPLEMENTS

- **High Calorie Milk Shakes:** (512 calories)

- 1 cup ice cream
- 4 ounces whole milk
- 2 Tbsp. non-fat dry-milk powder
- 1 Tbsp. vegetable oil

Flavoring: vanilla, chocolate syrup or powder, etc.



- **Almost Milk-Free Shakes:** (433 calories)

- 1 cup sherbet
- 1/2 cup Sprite
- 1/2 cup Cool-Whip

- **Instant Breakfast Milk Shakes:** (580 calories)

- 1 package flavored instant breakfast
- 1/2 cup Half & Half
- 1 cup ice cream

- **Granola Bars**

- **Sandwiches:** tuna, cheese, peanut butter and jelly, chicken salad, ham and cheese

- **Trail Mix:** (1808 calories)

- 1/4 cup sunflower seeds
- 1/2 cup raisins
- 1/2 cup dry roasted peanuts
- 1/2 cup M&M's

- **Fresh Fruit:**

Serve fruit with peanut butter, cottage cheese, yogurt or milk (to boost calories and add protein)



- **Yummy Pudding:** (250 calories, 8 g protein)

- 1 package vanilla instant pudding (or any flavor)
- 2 packages vanilla instant breakfast (or any flavor)
- 2 cups whole milk
- 2 teaspoons vegetable oil

Add vegetable oil to milk. Mix liquids, pudding mix and instant breakfast together; follow directions on pudding package.

## **ALTERNATIVES TO AN ORAL DIET**

There are special ways to provide your child with nutrition if he/she is unable to eat enough food by mouth. Alternatives to an oral diet are: Total Parental Nutrition (TPN) and external feedings. Both methods are capable of delivering total nutrition support until an oral diet becomes tolerable.

- External Feedings: Nutritional formulas can be given through small tubes that are placed into the nose and passed to the stomach.
- TPN: is a solution that contains protein, carbohydrate and fat, that is administered through a vein or central line when nutrition problems arise and your child cannot eat food by mouth and cannot tolerate tube feedings.



## **Financial Information/Financial Services**

### **How will we pay for my child's treatment?**

- Your first thought is to do everything you can to help your child. Your next concern may be the cost of the medical care and how you will pay for it.
- There may be financial aid available for medical bills for eligible families. See your social worker.

### **What if we have health insurance?**

- If you have health insurance call the insurance company or your employer to find out the coverage details. By calling the customer service phone number, you can **request a case manager** be assigned to your child's case. This will allow you to have one person at your insurance company who will be your main contact for any coverage issues related to your child's medical care.
- If your child has an unexpected admission to the hospital, it is very important that you call your insurance company. This is called PRE-CERTIFICATION. If you don't call them or wait too long, the insurance company can make you pay all or most of the bill. If you have any problems with your insurance company, or you are unable to pay your part, contact one of our financial counselors.
- It is **YOUR** responsibility to obtain your referral to a specialist at the time of the visit.
- Ask your primary care physician to give you enough referrals so you don't have to go back to their office frequently.
- You will need more than one referral because there can be a bill from a physician and a facility charge.
- You should be aware of any limitations on your policy, particularly if there is a calendar and/or a lifetime maximum of services.

### **But what if we don't have health insurance?**

If you do not have insurance, there are several programs that may be able to help your child. Financial counselors at the hospital and clinic will talk to you about your family's financial situation to determine if your child is eligible for any of these programs.

If you do not have health insurance, you may be eligible for Medicaid or Children's Medical Services (CMS). These programs have income limits. If you do not qualify for these programs, financial counselors in the hospital and clinic are available for assistance.

### **Why do we get so many bills?**

About a month after your child has been a patient at Nemours Children's Specialty Care or Wolfson Children's Hospital, you will begin to get bills. These bills will come from several places:

- You will receive a bill each time your child is admitted to the hospital. Your outpatient visits will be billed on a regular basis.
- You may also receive bills from any private doctors, labs, radiology, and radiation therapy that care for your child.

### **What should we do with these bills?**

If you have insurance, the hospital and the clinic will send a bill to your insurance company. After the insurance company has paid its share, you will be billed for your share. At that time, you will need to pay your share or make payment arrangements.

If you are on a government program, you may not have to pay these bills. If you continue to get bills, you should call the phone number on the bill, tell them which government program your child is eligible for and give them your child's policy number.

***WE SUGGEST YOU KEEP ALL OF YOUR CHILD'S BILLS, ARRANGED BY MONTH, IN A FOLDER, BINDER, OR ENVELOPE.***

## **Financial Information/Financial Services**

### Nemours Children's Specialty Care

Financial Office: 904.697.3721

### Baptist Medical Center / Wolfson Children's Hospital

Financial Office: 904.202.2092

### Financial Literacy Program

The Tom Coughlin Jay Fund Financial Game Plan helps families understand and manage the financial challenges they face, offering quarterly seminars and provides a Financial Coach who will meet one on one with families to discuss their specific questions and concerns.

Contact your social worker for more information.

## **Insurance Information**

It seems impossible for anyone to remember everything about their insurance. This reference page will help you keep important information at your fingertips.

Call your insurance company or employee benefits coordinator at work and get the facts in terms you can understand. Keep this sheet in this notebook and a copy in your child's bill folder. The financial counselor may assist you in completing this information for each insurance policy covering your child.

---

Insurance Company \_\_\_\_\_

Policy Holder \_\_\_\_\_

Policy # \_\_\_\_\_ Group # \_\_\_\_\_

Effective Date \_\_\_\_/\_\_\_\_/\_\_\_\_

Deductible \$ \_\_\_\_\_

Policy Limits:

Percentage Covered

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Amount Covered

\$ \_\_\_\_\_

\$ \_\_\_\_\_

\$ \_\_\_\_\_

Out Patient % covered \_\_\_\_\_

Day Surgery % covered \_\_\_\_\_

Psychiatric care % covered \_\_\_\_\_ (out patient) \_\_\_\_\_ (In patient)

Maximum Lifetime Limit Amount \$ \_\_\_\_\_

Does this policy require a second opinion? \_\_\_\_\_

Does this policy require pre-certification? \_\_\_\_\_

Pre-certification Phone #: \_\_\_\_\_

If you have any questions or problems, whom do I call?

Name: \_\_\_\_\_ Phone # (\_\_\_\_) \_\_\_\_\_

Notes: \_\_\_\_\_

## **Support Groups**

Families who have a child diagnosed with cancer may sometimes feel overwhelmed, frightened and alone. There are several groups that have been organized to help you through the days ahead. Support groups offer a time for people to connect with others facing similar situations, for learning they are not alone and for joining others who really understand. For more information on a particular group the Social Worker at the hospital or clinic can assist you.

### **Mothers For Hope & Fathers For Hope:**

These groups are underwritten by the Child Cancer Fund for parents/guardians with a child on or off treatment for cancer. Contact Carla at the Child Cancer Fund for more information – 904-396-4223.

### **Adolescent & Young Adult Program:**

This program is coordinated by a Pediatric Oncologist, Social Workers, and Child Life Specialist from Nemours Children's Specialty Care. Contact your Social Worker or Child Life Specialist for more information.

### **Sibling Program (JAYS)**

The Tom Coughlin Jay Fund Foundation offers a unique program for siblings of children with cancer. J.A.Y.S. (Just Among You Siblings) Team is a psychosocial program with educational components that offer evidence-based comprehensive, personalized support to the school-aged and teenage siblings of pediatric patients.

### **Camp Boggy Creek:**

- **Summer Camp** – Children ages 7-16 years who are diagnosed with cancer are eligible for this summer camp program. During the week your child is at camp, he/she will have medical personnel available for care. The Nemours Children's Specialty Care and Wolfson Children's Hospital Child Life Specialist can provide additional information.
- **Family Retreat Weekend** – the Child Cancer Fund sponsors a Family Retreat Weekend in the Fall for the patient and immediate family at Camp Boggy Creek. The Nemours Children's Specialty Care Child Life Specialist can provide additional information.



# CAN'T AFFORD A TUTOR? NOW YOU CAN!



## **Spiller Educational Support Program**

The Child Cancer Fund's Spiller Educational Support Program provides funding to families to hire a tutor for their child.

Ask your social worker for further information, eligibility requirements, and how to apply.





Their *courage*  
is our *inspiration.*

***It's unfair:*** No child should have to face the fear, the pain and the ordeal of cancer. The Child Cancer Fund is a nonprofit organization devoted to helping children and their families in Northeast Florida and Southeast Georgia through the challenges of childhood cancer.

## How we help.

**Child Life Specialist Position:** Our core program funds the Child Life Specialist position at Nemours Children's Specialty Care. Through play, learning and self-expression, children learn to minimize the stress of treatment. The advocate works with children and their families, helping them cope with the often frightening treatment for childhood cancer.

**Financial Assistance:** A diagnosis of childhood cancer often means financial hardship for the families. We help with expenses for housing, utility bills, food and other expenses that health insurance does not cover.

**Support Services:** We offer families the emotional and practical support they need to make it through this challenging experience. We also host an annual family retreat weekend.

**The Christy Fund:** Established in memory of a child of extraordinary courage and unconquered spirit, the Christy Fund is a restricted account for the Child Life Specialist position. Please read Christy's inspirational story on our website at [childcancerfund.org](http://childcancerfund.org).

## How you can help.

Please send your donations to the address below or visit our website for online donations and additional information. Thank you.



 [facebook.com/ChildCancerFund](https://facebook.com/ChildCancerFund)

 United Way  
of Northeast Florida



**Donate today at [ChildCancerFund.org](http://ChildCancerFund.org)**

4720 Salisbury Road • Jacksonville, FL 32256 • phone 904-396-4223





Our mission is to help families tackle childhood cancer by providing comprehensive financial, emotional, and practical support. From diagnosis to recovery and beyond, we are part of the team, allowing parents to solely focus on their child's well being. Our goal is to BE THERE for parents facing the unthinkable so they can BE THERE for their families.

## FINANCIAL, EMOTIONAL, AND PRACTICAL SUPPORT

From helping with household bills to financial game planning to simply making a child's life brighter, we're here for parents so they can BE THERE for their child.

## FINANCIAL ASSISTANCE AND GAME PLANNING

The Jay Fund takes the financial burden and stress off families by helping with expenses; such as mortgages, rent, car, electric, water, phone, food, and other household expense payments during a time of crisis. But it goes beyond that. We offer quarterly seminars to give information and insight on managing finances. We also provide a Financial Coach who will meet one on one with families to discuss their specific questions and concerns. We'll BE THERE to answer financial questions so families can make it through this costly process financially intact.

The Jay Fund also offers scholarships to brave patients and survivors who wish to continue their education. We'll BE THERE to help them achieve their dreams.

## MAKING A CHILD'S LIFE BRIGHTER

The financial support we provide is invaluable to families. But the emotional support is equally important to our mission. We offer once-in-a-lifetime opportunities that simply make a child's life brighter and create happy memories. We also host special, fun events so families and children can come together with others facing the same challenges. This enables families battling childhood cancer to BE THERE for each other with emotional support, love and friendship.

## QUALITY OF LIFE

Another important way we can BE THERE for families is to support treatment facilities that help improve quality of life for the patient and families. Our grants support child psychology services, Child Life programs, Art with a Heart program funding, survivorship programs, special medical equipment, entertainment, games and more at outpatient and inpatient centers.





## THE TOM COUGHLIN JAY FUND

Recognizing that childhood cancer affects the entire family, the Tom Coughlin Jay Fund Foundation offers a unique program for siblings of children with cancer. J.A.Y.S. (Just Among You Siblings) Team is a psychosocial program with educational components that offer evidenced-based comprehensive, personalized support to the school-aged and teenaged siblings of pediatric patients.

## THE OBJECTIVE OF J.A.Y.S. TEAM

The Jay Fund wants to help increase the scope of current emotional support to families who are tackling childhood cancer by ensuring that siblings going through this experience are provided with opportunities for peer support and education.

## SUPPORT FROM J.A.Y.S. TEAM

**MEET** other siblings in a relaxed, recreational setting.

**DISCUSS** common joys and concerns with other siblings of children with cancer.

**DISCOVER** how others handle situations that are commonly experienced by siblings of children with cancer.

**LEARN** more about their sibling's diagnosis, treatment, and other implications of childhood cancer.

## FINANCIAL, EMOTIONAL, AND PRACTICAL SUPPORT

The Tom Coughlin Jay Fund Foundation's mission is to help families tackle childhood cancer by providing comprehensive financial, emotional, and practical support. From diagnosis to recovery and beyond, we are part of the team, allowing parents to solely focus on their child's well-being. Our goal is to BE THERE for parents facing the unthinkable so they can be there for their families.



For more information about J.A.Y.S. Team visit [www.tcjayfund.org](http://www.tcjayfund.org) or 904-543-2599





## **WEB ADDRESSES**

American Cancer Society	<a href="http://www.cancer.org">http://www.cancer.org</a>
American Institute for Cancer Research	<a href="http://www.aicr.org">http://www.aicr.org</a>
American Dietetic Association	<a href="http://www.eatright.org">http://www.eatright.org</a>
CancerCare	<a href="http://www.cancercare.org">http://www.cancercare.org</a>
Candlelighters Childhood Cancer Foundation	<a href="http://www.candlelighters.org">http://www.candlelighters.org</a>
CarePages	<a href="http://www.carepages.com">http://www.carepages.com</a>
Child Cancer Fund	<a href="http://www.childcancerfund.org">http://www.childcancerfund.org</a>
Childhood Leukemia Foundation	<a href="http://www.clf4kids.org">http://www.clf4kids.org</a>
Children's Brain Tumor Foundation	<a href="http://www.cbtf.org">http://www.cbtf.org</a>
CureSearch (NCCF/COG)	<a href="http://www.curesearch.org">http://www.curesearch.org</a>
Dreams Come True	<a href="http://www.dreamscometrue.org">http://www.dreamscometrue.org</a>
Fertile Hope	<a href="http://www.fertilehope.org">http://www.fertilehope.org</a>
KidsHealth	<a href="http://www.kidshealth.org">http://www.kidshealth.org</a>
Leukemia & Lymphoma Society	<a href="http://www.leukemia-lymphoma.org">http://www.leukemia-lymphoma.org</a>
National Cancer Institute	<a href="http://www.cancer.gov">http://www.cancer.gov</a>
National Children's Cancer Society	<a href="http://www.nationalchildrenscancersociety.com">http://www.nationalchildrenscancersociety.com</a>
National Institutes of Health	<a href="http://www.nih.gov">http://www.nih.gov</a>
Nemours Children's Clinic	<a href="http://www.nemours.org">http://www.nemours.org</a>
Kids Eye Cancer	<a href="http://www.kidseyecancer.org">http://www.kidseyecancer.org</a>
Patient Advocate Foundation	<a href="http://www.patientadvocate.org">http://www.patientadvocate.org</a>
Patient Services Incorporated	<a href="http://www.uneedpsi.org">http://www.uneedpsi.org</a>
Planet Cancer	<a href="http://www.planetcancer.org">http://www.planetcancer.org</a>
Tom Coughlin Jay Fund Foundation	<a href="http://www.tcjayfund.org">http://www.tcjayfund.org</a>
Wolfson Children's Hospital	<a href="http://www.wchjax.co">http://www.wchjax.co</a>

## **Resources**

### **American Brain Tumor Association**

2720 River Rd., Suite 146  
Des Plaines, IL 60018  
847-827-9918 – Fax 847-827-9918  
1-800-886-2282  
[www.abta.org](http://www.abta.org)

### **American Cancer Society**

1430 Prudential Dr.  
Jacksonville, FL 32207  
Duval: 904-398-0537  
Beaches: 904-249-0022  
Clay County: (904) 264-6039  
[www.cancer.org](http://www.cancer.org) (In My Community)

Florida: 1-877-258-2619  
Georgia: 1-800-282-4914  
National: 1-800-227-2345

### **American Institute for Cancer Research**

1759 R Street, N.W.  
Washington, DC 20077-3618  
202-328-7744  
[www.aice.org](http://www.aice.org)

### **Angel Flight, Inc.**

1515 East 71st Street, Ste. 312  
Tulsa, OK 74136  
918-749-8992

### **Cancer Care, Inc.**

1180 Avenue of the Americas, 2<sup>nd</sup> Fl.  
New York, N.Y. 10036  
212-221-3300  
[www.cancercare.org](http://www.cancercare.org)

### **Cancer Information Service of the National Cancer Institute**

1-800-422-6237  
[www.nci.nih.gov](http://www.nci.nih.gov)

### **Cancer Legal Resource Center**

1-866-843-2572

### **Candlelighters Childhood Cancer Foundation National Headquarters**

P.O. Box 498  
Kensington, MD 20895-0498  
1-800-366-2223  
[www.candlelighters.org](http://www.candlelighters.org)

### **Child Cancer Fund**

4720 Salisbury Road  
Jacksonville, FL 32256  
904-396-4223  
[www.childcancerfund.org](http://www.childcancerfund.org)

### **Childhood Leukemia Foundation**

807 Mantoloking Rd., Suite 203  
Brick, New Jersey 08723  
1-888-253-7109

### **Children's Brain Tumor Foundation**

274 Madison Ave., Suite 1301  
New York, NY 10016  
1-866-228-4673  
[www.cbtf.org](http://www.cbtf.org)

### **Corporate Angel Network**

Westchester County Airport  
One Loop Road  
White Plains, NY 10604-1215  
1-866-328-1313  
[www.corpangelnetwork.org](http://www.corpangelnetwork.org)

### **CureSearch**

National Childhood Cancer Foundation  
4600 East West Highway, Suite 600  
Bethesda, MD 20814-3457

### **CureSearch**

Children's Oncology Group  
Research Operations Center  
440 E. Huntington Drive  
P.O. Box 60012  
Arcadia, CA 91066-6012  
1-800-458-6223

### **Dreams Come True**

6803 Southpoint Parkway  
Jacksonville, FL 32216  
904-296-3030  
[www.dreamscometrue.org](http://www.dreamscometrue.org)

**The Blood Alliance**

904-353-8263  
1-888-447-1479  
[www.igiveblood.com](http://www.igiveblood.com)

**Leukemia & Lymphoma Society  
Local Chapter**

7077 Bonneval Rd., Suite 610  
Jacksonville, FL 32216  
904-332-6414  
[www.lls.org](http://www.lls.org)

Georgia: 770-438-6006  
National: 1-800-868-0072

**National Cancer Institute**

NCI Public Inquiries Office  
6116 Executive Boulevard  
Room 3036A  
Bethesda, MD 20892-8322  
1-800-422-6237

**National Children's Cancer Society**

1015 Locust, Suite 600  
St. Louis, MO 63101  
1-800-532-6459

**National Coalition for Cancer Survivorship**

1010 Wayne Ave., Suite 770  
Silver Spring, MD 20910  
877.622.7937  
[www.canceradvocacy.org](http://www.canceradvocacy.org)

**National Foundation for Cancer Research**

4600 East West Highway, Suite 525  
Bethesda, MD 20814  
1-800-321-2873  
[www.nfcr.org](http://www.nfcr.org)

**Patient Advocate Foundation**

753 Thimble Shoals Blvd., Suite B  
Newport News, VA 23606  
1-800-532-5274

**National Institutes of Health**

9000 Rockville Pike  
Bethesda, Maryland 20892  
1-800-422-6237

**PedsCare**

4266 Sunbeam Rd.  
Jacksonville, FL 32257  
904-596-6505  
[www.communityhospice.com](http://www.communityhospice.com)

**Ronald McDonald House  
Local Chapter**

824 Children's Way  
Jacksonville, FL 32207  
904-807-4663  
[www.rmjax.org](http://www.rmjax.org)

**Tom Coughlin Jay Fund Foundation**

P.O. Box 50798  
Jacksonville, FL 32240  
904-543-2599  
[www.tcjayfund.org](http://www.tcjayfund.org)



## **Childhood Cancer Book List**

There is printed material produced by the American Cancer Society, National Cancer Institute and the Candlelighters Childhood Cancer Foundation that are helpful for educators and parents addressing the issues faced when the student has cancer. Each family can receive a free copy of "Educating the Child with Cancer" by writing to the Candlelighters Childhood Cancer Foundation 7910 Woodmont Ave., Suite 460, Bethesda, MD. 20814-3015.

### **Children's Books**

*An Alphabet about Kids with Cancer*, Bergiund, R. The Children's Legacy, Denver, CO.

*Kathy's Hats: A Story of Hope*, Krisher, T., Albert Whitman & Co., Morton Grove, ILL.

*Moonbeam: A Book of Meditations for Children*, Garth, M. Colins Dove, a division of Harper Collins Publishers, North Blackburn, Victoria 3130, Australia.

My Book for Kids with Cancer. A Child's Autobiography of Hope. Gaes, J. Melius and Peterson Publishing, Inc. Aberdeen, South Dakota

*What About Me? When Brothers and Sister Get Sick*, Peterkin, A., Magination Press, N.Y.

*I Want to Grow Hair, I Want To Grow Up, I Want To Go To Boise*, Bombeck, E., Harper and Row, Publishers, New York. Free copies available to families of children with cancer from the American Cancer Society.

### **Adult Books**

*A Child Shall Lead Them, Lessons in Hope From Children With Cancer*, Komp, D, Zondervan Publishing House, Grand Rapids, MI.

*A Parent's Guide to Childhood Cancer*, Bain, L., Dell Publishing, N.Y.

*Childhood Cancer and the Family*, Chesler, M., and Barbarin, O., Brunner/Mazel Publishers, N.Y.

*Childhood Cancer: Understanding and Coping*, Ekert, H., Gordon and Brench Science Publishers, New York.

*Coping with Childhood Cancer: Where do We Go From Here*: Adams, D., and Deveau, E., Kimbridge Publications, Ontario, Canada.

*Living with Childhood Cancer*, Spinetta, J. and Deasy-Spinetts, P., eds., The C.V. Mosby Co., St. Louis, MO.

*The Cure of Childhood Leukemia: Into the Age of Miracles*, Laszlo, J., Rutgers University Press, N.J.

*Your Child Has Cancer: A Guide To Coping*, Rolsky, J., committee to Benefit the Children, St. Christopher's Hospital for Children, Philadelphia, PA.

*Children with Cancer: A Comprehensive Reference Guide for Parents*: Bracken JM, 1986, Oxford University Press, N.Y.

## **Nutrition Books:**

*Eating Hints: Recipes and Tips for Better Nutrition During Cancer Treatment.* U.S. Department of Health and Human Services. Clinical Nutrition Department at Children's Medical Center. (See the dietitian for a copy of this book.)

*Nutrition for Patient Receiving Chemotherapy and Radiation Treatment,* American Cancer Society (ACS), Local Office of the ACS.

## **Childrens Oncology Group (COG) Online Resource:**

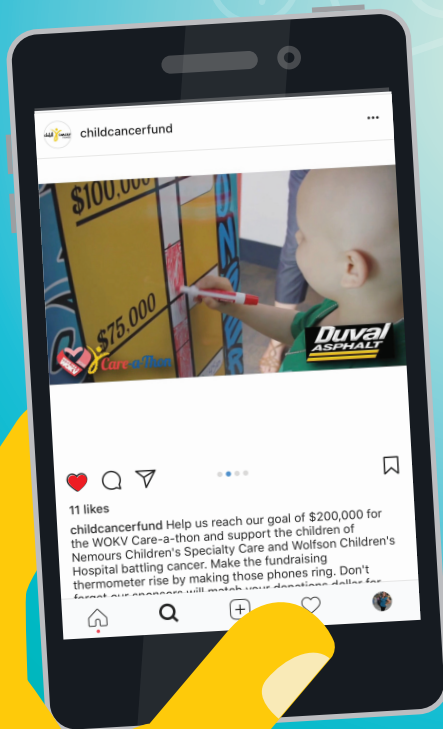
*Children's Oncology Group Family Handbook*, available for E-Readers **free of charge** in English, Spanish, and French. Links to download the E-Book versions to iBooks, Kindle, and other E-Readers can be found on the COG webpage at:

<http://www.childrensoncologygroup.org/index.php/cog-family-handbook>

This *COG Family Handbook* is a valuable resource for families as they navigate their child's cancer journey, providing reliable information about treatment, support and follow-up care.



TOGETHER WE ARE  
**#STRONGERTHANCANCER**



**JOIN US ON SOCIAL MEDIA!**

 [Facebook.com/ChildCancerFund](https://www.facebook.com/ChildCancerFund)

 [@ChildCancerFund](https://www.instagram.com/ChildCancerFund)

 [@CCFJacksonville](https://twitter.com/CCFJacksonville)





# CHILDREN'S CANCER RESOURCES AT YOUR FINGERTIPS.

Everyone deserves a little help, especially when it comes to managing a cancer diagnosis. A central location where a child's network of caregivers can store information and access it from anywhere including the doctor's office, hospital, work or home... A way to share that information with those that need it – and most importantly, when they need it.

Introducing the CancerCare mobile app – a personal cancer caregiver assistant. After downloading the app, you will have quick access to a simple dashboard allowing you, your family and other caregivers to:

- **Organize** treatment dates and medication schedules all in one place; and automatically synchronize it with your mobile calendar.
- **Track** patient mood, side effects and blood counts, in real time.
- **View** reports to see trends.
- **Access** Cancer Care Resources right from the app.
- **Confidentially share** all of this information with other family caregivers. Dad can add side effects and mom will see it on her phone.

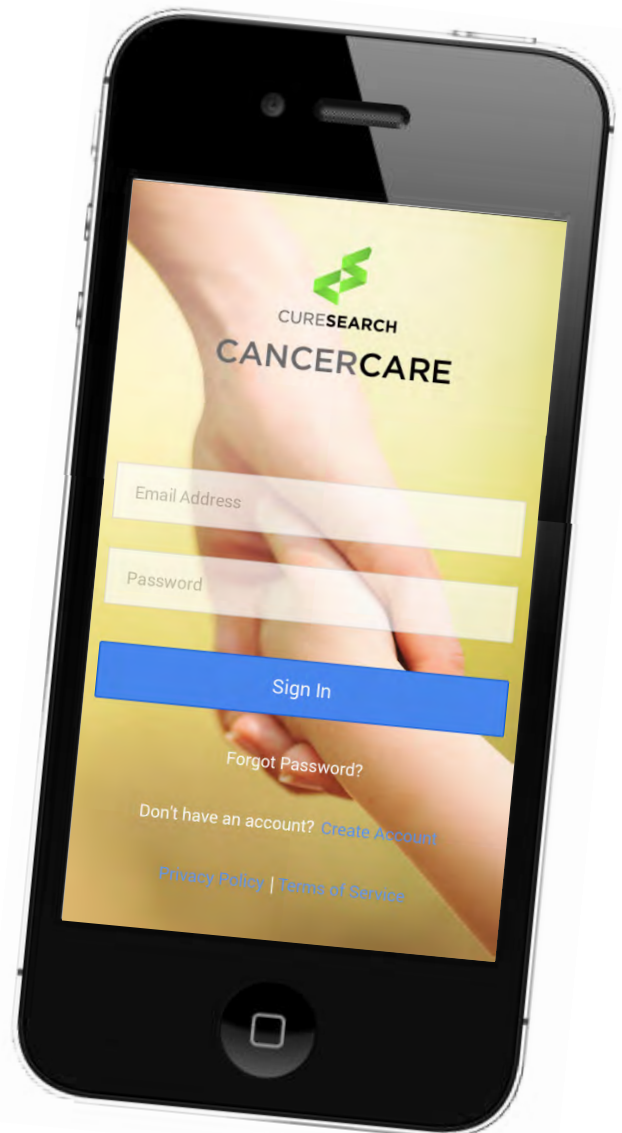
Best of all, it's free with no in-app purchases or ads. Get your FREE personal cancer caregiver assistant today.



Need or want to learn more before downloading or sharing with others? Visit [curesearch.org/app](http://curesearch.org/app) to read testimonials, take a tour of the features in our CancerCare app video, or see screenshots of what's inside your personal CancerCare assistant.

Have questions or feedback to share? Let us know.

Until There Are Cures,  
Laura Thrall  
CEO, CureSearch for Children's Cancer



CureSearch for Children's Cancer | [info@curesearch.org](mailto:info@curesearch.org)

4600 East West Hwy., Suite 600, Bethesda, MD 20814 | (800) 458-6223

## **Long Term Follow-Up**

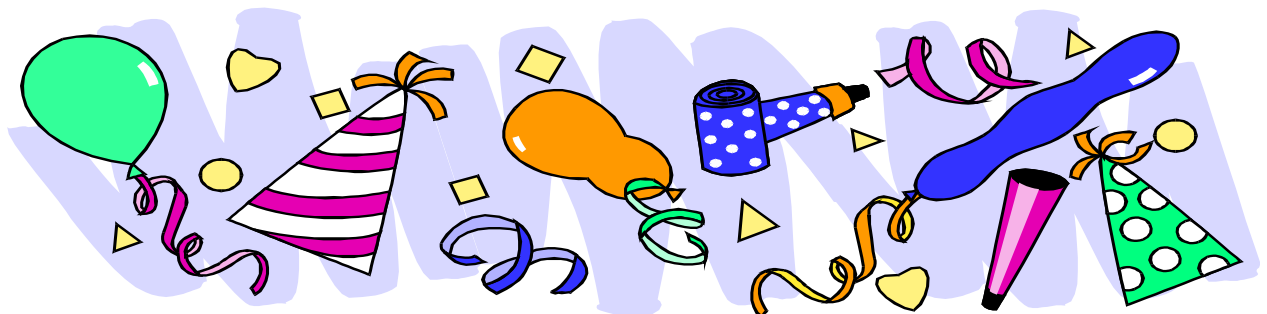
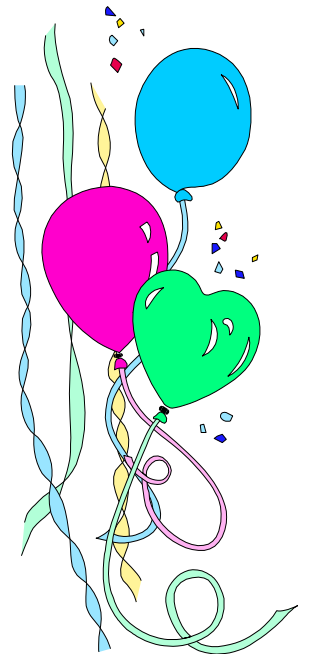
Great strides have been made in the treatment of childhood cancer. Improved cure rates are brought about as a result of more effective and intensive treatment. Many children survive and go on to have children of their own.

Unfortunately with greater cure rates brought on by intensive therapy comes the risk of late effects of cancer treatment. Therefore, it is our responsibility as providers of care to these children and young adults, to look at the possible consequences of treatment and offer our services to them in dealing with the late effects.

A comprehensive long term follow-up clinic/program will continue to follow your child after treatment ends until the age of 21. This program will offer a team approach to evaluate possible side effects to treatment and intervention opportunities. Intervention may include referral to appropriate specialists, counseling and support groups.

Some day it may be possible to prevent late effects completely. Our purpose today is early identification and intervention of possible problems.

The overall goal is to help all the survivors lead healthy, well adjusted lives.





## **Glossary**

### **A**

<b>Acute:</b>	Rapidly developing; quick, sudden.
<b>Adjuvant Chemotherapy:</b>	The use of drugs in addition to surgery and/or radiation to treat cancer.
<b>Afebrile:</b>	No fever. Normal temperature.
<b>Alopecia:</b>	Temporary loss of hair after receiving some type of chemotherapy or radiation.
<b>Absolute Neutrophil Count (ANC):</b>	The number of neutrophils (infection fighting white blood cells) in a white blood cell count.
<b>Acyclovir:</b>	An antiviral medicine used to fight viral infections.
<b>Ampho-B or Amphotericin B</b>	An antifungal medicine used to fight fungal infections
<b>Anemia:</b>	A condition in which there is a decreased number of red blood cells. Symptoms include fatigue, weakness, pallor, shortness of breath, and a fast heartbeat.
<b>Anesthesiologist:</b>	The physician who uses certain drugs to keep a patient unconscious during surgery.
<b>Anorexia:</b>	Absence or loss of appetite for food.
<b>Antibiotics:</b>	Medication used to treat bacterial infection.
<b>Antibody:</b>	A protein produced by the body to fight against viruses and bacteria.
<b>Antiemetic:</b>	Medicines that reduce nausea and vomiting.
<b>Antigen:</b>	A foreign body that stimulates an immune response, such as forming an antibody specific for that substance.
<b>Ascites:</b>	Accumulation of fluid in the abdominal cavity.
<b>Asymptomatic:</b>	No signs or indications of a disease.
<b>Ataxia:</b>	Loss of coordination, resulting in a tendency to stagger.

## **B**

<b>Bacteria:</b>	Organisms that grow in body tissues. Serious bacterial infections may occur in children with cancer and need treatment with intravenous antibiotics. Staph and Strep infections are examples of bacterial infections.
<b>Benign:</b>	A growth or tumor that is not cancerous; one that does not usually invade and destroy neighboring tissue or spread to other parts of the body.
<b>Bilateral:</b>	Pertaining to both sides of the body.
<b>Biopsy:</b>	The removal of a small portion of tissue to examine under the microscope.
<b>Blasts:</b>	Young/immature white blood cells that fail to mature into cells which have specific functions in the body.
<b>Blood Culture:</b>	Blood test taken from a vein or catheter used to determine the presence of bacteria in the blood.
<b>Bone Marrow:</b>	The material in the middle of bones that produces most of the blood cells.
<b>Bone Marrow Aspiration:</b>	The insertion of a needle into the bone to withdraw bone marrow through a syringe.
<b>Bone Marrow Biopsy:</b>	A test where a very small piece of bone is removed.
<b>Bone Marrow Suppression:</b>	Lower than normal amounts of blood cells in bone marrow due to disease or treatment.
<b>Bone Marrow Transplant:</b>	A process by which bone marrow, either from a donor or oneself, is transplanted into a person who is not making enough healthy blood cells.
<b>Broviac/Hickman Catheter:</b>	A special implanted intravenous catheter which allows medicines, fluids, and blood products to be given and blood samples to be drawn.

## **C**

<b>Calorie:</b>	A measurement of the energy the body gets from food. Calories provide "fuel" for body functions, such as breathing, blood circulation and physical activity.
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<b>Cancer:</b>	The general term for diseases characterized by the uncontrolled growth of abnormal cells. Also called malignant neoplasm or malignancy.
<b>Catheter:</b>	A tube used for injection or withdrawal of fluid.
<b>CAT Scan:</b>	Diagnostic x-ray procedure in which a computer is used to generate a three dimensional image.
<b>Complete Blood Count (CBC):</b>	An examination of a sample of blood used to count the number of red cells, white cells, and platelets.
<b>Cells:</b>	The basic structure of all living matter.
<b>Central Line:</b>	A catheter placed into a large vein, through which blood can be drawn and intravenous treatment administered.
<b>Central Nervous System (CNS):</b>	The brain and spinal cord.
<b>Central Venous Catheter:</b>	A small hollow flexible tube which is inserted into a large vein to be used for taking blood samples or giving blood products or medications.
<b>Chemotherapy:</b>	Medicines used to treat a disease, especially cancer. Chemotherapy is used to destroy the cancer cells and/or keep them from reproducing.
<b>Chronic:</b>	Continuous or of long duration.
<b>Clinical Trial:</b>	A research study in which patients are treated according to a protocol. Therapies are improved and refined based on results of clinical trials.
<b>Combination Chemotherapy:</b>	The use of several drugs at the same time or in a particular order to treat cancer.
<b>Conscious Sedation:</b>	Medication given IV or by mouth to help the child relax and feel sleepy during procedures. The child will have a decreased level of consciousness but will be able to respond to physical touch and voices.
<b>Consent Form:</b>	A written description of the method of treatment and the medications used to treat the patient. The parent/ guardian must sign in to verify agreement of services.
<b>Cultures:</b>	Tests which are run on blood, urine, stool, sputum, and any body tissue to detect infection.

**Cytomegalovirus (CMV):**

A type of virus that usually is not harmful in healthy individuals. Can cause problems especially pneumonia, in people with low resistance to infection.

**D**

**Dehydration:**

Excessive loss of fluids from the body.

**Diagnosis:**

The identification of a disease.

**Diet:**

Consists of the foods you eat, including both liquids and solids.

**Dietary Fat:**

A nutrient that supplies calories (energy) to the body. Fat also helps the body absorb certain vitamins. Small amounts of fat are necessary for normal body function. Foods high in fat are also high in calories.

**Dysphagia:**

Difficulty in swallowing.

**E**

**Echocardiogram (Echo):**

Test to study the heart.

**Edema:**

An accumulation of fluids within the body's tissues.

**Electroencephalogram (EEG):**

A test to study the electrical activity of the brain.

**Electrocardiogram (EKG):**

A test to study the electrical activity of the heart.

**Electrolytes:**

A general term for the minerals necessary to give the body the proper fluid balance.

**Emesis:**

Vomit.

**Engraftment:**

The time period after the bone marrow has been infused and begins to reproduce new cells.

**Etiology:**

The study of the cause of disease.

**F**

**Febrile:**

Fever. Elevated body temperature 101<sup>0</sup> F or greater by mouth, ear, or under arm

**Fellow:** A physician who has completed medical school, internship and residency and is doing further study to become a specialist.

**Fortified:** A method of adding extra nutrients to food.

**Fungus:** An organism that can cause serious infections.

## **G**

**Gastrointestinal:** Having to do with the digestive tract, including the stomach and the intestines.

**Gastrostomy Tube (G Tube):** A tube surgically placed into the stomach. Used to give high calorie formulas.

**Glucose:** A simple sugar occurring in some fruits and honey. The sugar found in blood.

**Graft-Versus-Host Disease (GvHD):** A rejection process whereby the transplanted bone Marrow (the graft) attacks tissues in the recipient (the host). The organs usually affected are the skin, gastrointestinal tract and liver.

**Granulocytes:** The type of white blood cells that help to protect against bacterial infection. Also known as polys, segs, neutrophils.

**Growth Factor:** A substance that is normally produced by the body that helps your white blood cells grow faster.

## **H**

**Hematocrit (HCT):** The percentage of red cells in the blood.

**Hematologist:** A physician who is a specialist in the study of blood and blood disorders.

**Hematology:** The study of blood and blood disorders.

**Hematuria:** Blood in the urine.

**Hemoglobin (Hgb):** The substance in red blood cells that carries oxygen to tissues of the body.

<b>Hemorrhage:</b>	Loss of blood from the body brought about by injury or by lack of certain elements of the blood, such as platelets.
<b>Herpes:</b>	A group of viruses, including herpes simplex, herpes zoster, or shingles. A virus that usually produces fluid-filled blisters on the skin and mucous membranes.
<b>HLA Typing:</b>	The process of identifying the genetic structure of circulating white blood cells. HLA typing, also known as tissue typing, is performed to determine whether a donor can be found for a bone marrow transplant. Blood is removed from a vein for this test.
<b>Hospice Care:</b>	Hospice care provides a comprehensive system of care (pain & symptom management, spiritual, psychosocial, and bereavement support) for families whose child has months or weeks left of life (this is often referred to as terminally ill).
<b>Hydration:</b>	Giving fluids to a patient, orally or intravenously.
<b>Hyperalimentation:</b>	An intravenous solution with a high nutritional content given in place of oral food intake when someone is unable to eat. Also called total parental nutrition (TPN).
<b>I</b>	
<b>Intramuscular (IM):</b>	Meaning "in the muscle". Usually refers to the type of injection.
<b>Immune System:</b>	A system that protects the body from diseases and infections. Includes the bone marrow, blood, thymus gland, lymph nodes, and spleen.
<b>Immunity:</b>	Defense against a particular infection.
<b>Immunosuppression:</b>	Increased susceptibility to infection.
<b>Implantable Venous Device (IVAD):</b>	A type of central venous catheter. A small device called a port, which is placed beneath the skin. Is used to deliver medications into the bloodstream.
<b>Indigestion:</b>	Upset stomach.
<b>Infection:</b>	A condition in which disease producing organisms invade and multiply in the body. Infections can occur in any part of the body. They may cause fever and other problems depending on the site of the infection.

<b>Infusion:</b>	Injecting fluid into a vein or artery.
<b>Injection:</b>	The use of a syringe to "push" fluids into the body; often called a "shot".
<b>Intern:</b>	A physician in his first year of training after completing medical school.
<b>Intrathecal:</b>	Administration of medication into the central nervous system by lumbar puncture.
<b>Intravenous:</b>	Within or into a vein.
<b>Investigational Drugs:</b>	Medications that are used for treatment in which all the side effects may not be known.
<b>Irradiated Blood Products:</b>	Blood products that have been exposed to radiation to inactivate the lymphocytes, which could otherwise cause graft-versus-host disease.
<b>Isolation:</b>	A special room where the child stays alone to protect others from an infection the child has or to protect the child from exposure to infection.

## **J**

<b>Jaundice:</b>	A yellowish color of the skin and white portion of the eyes. Jaundice may be associated with liver problems or with increased breakdown (hemolysis) of red blood cells in the body.
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## **K**

## **L**

<b>Lesion:</b>	A change in tissue due to injury or disease.
<b>Lethargy:</b>	A feeling of sluggishness. Having very little energy.
<b>Leukocytes:</b>	All white blood cells.
<b>Leukocytosis:</b>	A total white blood cell count greater than 10,000.
<b>Leukopenia:</b>	A total white blood cell count less than 4,000.
<b>Lipids:</b>	High-caloric forms of fats that your body needs every day. They can be given through a vein, usually by a central venous catheter, along with TPN. Also called Intralipids.

**Lumbar Puncture (LP, Spinal Tap):**

The insertion of a needle into the space between the vertebrae (bones of the spinal column) to withdraw spinal fluid and/or give medication.

**Lymph Nodes:**

Sites where circulating lymph fluid is filtered before being returned to the bloodstream.

**Lymphocyte:**

A type of white cell found in the blood.

**Lytic Lesion:**

The breakdown or decomposition of a specific tissue or bone.

## **M**

**Malignant:**

Cancerous (not benign).

**Malnutrition:**

A condition in which the body receives too few of the essential nutrients (fats, protein, and carbohydrates).

**Metastasis:**

The spread of cancer from its original site.

**Minerals:**

Nutrients required by the body in small amounts such as iron, calcium and potassium.

**Monocyte:**

A type of white cell found in the blood.

**Magnetic Resonance Imagery (MRI):**

A diagnostic procedure utilizing a large magnet, radio waves, and a computer to produce a three-dimensional image.

**Mucositis:**

Inflammation of the mucous membranes (lining of the mouth) which may include areas of redness or painful sores.

## **N**

**Nadir:**

The lowest blood cell count of a patient resulting from illness or chemotherapy, usually following therapy. (This represents bone marrow suppression).

**Nasogastric Tube (NG Tube):**

A thin tube placed into the stomach by way of the nose used to give food and medicine.

**Neutropenia:**

Less than 1,000 neutrophils in the blood. The patient with fewer than 500 becomes more susceptible to infection.



**Neutrophil (Poly or Seg):**

A type of white blood cell. The most important cell for fighting bacterial infection.

**NPO:**

A Latin abbreviation for "nothing by mouth". This means the patient must have nothing to eat or drink.

**Nutrient:**

The part of food that the body uses to grow, function and stay alive. The major classes of nutrients that the body needs are proteins, minerals, fats, carbohydrates, and vitamins.

**O**

**Oncologist:**

A physician who has special training in identifying and treating cancer.

**Oncology:**

The study of cancer.

**P**

**Palliative Care:**

Palliative care is the active, comprehensive, interdisciplinary management of physical, emotional, social and spiritual needs of patients and families. The goals are to relieve suffering, promote function, provide support, and clarify goals of care, while providing the best quality of life as determined by the patient and family.

**Pancytopenia:**

A decrease in all types of cells in the blood.

**Pathologist:**

A doctor who studies cells and tissues to determine if a disease is present.

**Peripheral-Blood Stem Cell Transplant (PBSCT):**

A type of transplant in which circulating stem cells are collected and later infused back into a patient after very high doses of chemotherapy or radiation therapy have been given.

**Petechiae:**

Tiny hemorrhages of the small blood cells underneath the skin which indicate low platelets.

**Plasma:**

The liquid portion of the blood.

**Platelet:**

A blood cell that helps in blood clotting.

**PO:**

A Latin abbreviation for "by mouth". This means that food or medication is given orally.

**POG:**

Pediatric Oncology Group.

<b>Polys:</b>	A type of white blood cell that protects against bacterial infection.
<b>Potassium:</b>	A mineral the body needs for fluid balance and other essential functions.
<b>Port-A-Cath:</b>	An implanted catheter placed under the skin for the infusion of medications.
<b>Prognosis:</b>	A prediction of the course of disease. The future prospects of the patient.
<b>Prophylactic:</b>	Treatment to prevent a complication or an illness before it occurs.
<b>Protein:</b>	A nutrient that supplies calories (energy) to the body. Protein becomes part of muscle, bone, skin, and blood.
<b>Protocol:</b>	A plan of treatment for a specific disease.

## **Q**

## **R**

<b>Radiation:</b>	The application of high powered X-rays to part of the body to kill or injure the cancer cells. Often radiation is used along with chemotherapy to treat cancer.
<b>Recurrence:</b>	Reappearance of cancer at its original site or at a different site.
<b>Red Blood Cells (RBC):</b>	Cells that supply oxygen to tissues throughout the body.
<b>Reinduction:</b>	To start over (new treatment or protocol).
<b>Relapse:</b>	The reappearance of cancer after a disease-free period.
<b>Remission:</b>	The disappearance of signs and symptoms of disease. No disease can be detected.
<b>Resectable:</b>	A tumor which can be surgically removed.

## **S**

<b>Sarcoma:</b>	A cancer of the connective tissue such as bone, cartilage, fat, or muscle.
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<b>Shingles:</b>	Herpes Zoster, a virus that produces painful skin eruptions that follow the underlying route of the nerves inflamed by the virus.
<b>Sibling:</b>	Brother or sister.
<b>Side Effects:</b>	The after effects or secondary effects of treatment. For example, hair loss, mouth sores, and low white blood counts are all side effects of chemotherapy.
<b>Sodium:</b>	A mineral required by the body to keep body fluids in balance. Too much sodium can cause water retention.
<b>Spinal Tap:</b>	Lumbar puncture of the spinal cavity with a needle to extract the spinal fluid for tests.
<b>Spleen:</b>	The body organ to the left of the stomach that acts as a blood filter.
<b>Stomatitis:</b>	Sores in the mouth and lips.
<b><u>T</u></b>	
<b>Therapy:</b>	Treatment to eliminate or control a disease.
<b>Thrombocytopenia:</b>	A low platelet count that may result in abnormal bleeding.
<b>Tissue Typing:</b>	A series of tests done before BMT to determine how closely the tissues of a donor and the recipient match.
<b>Total Body Irradiation (TBI):</b>	Radiation treatment of the entire body.
<b>Toxicity:</b>	The side effects caused by some forms of chemotherapy.
<b>Total Parental Nutrition (TPN) :</b>	A solution containing vitamins, minerals, sugar, electrolytes, lipids, and proteins to support the patient's nutritional needs. Solutions are given through an IV or central venous catheter.
<b>Transfusion:</b>	Administration of blood or blood products through a peripheral IV or central venous catheter.
<b>Tumor:</b>	A growth or lump caused by cells growing in an abnormal manner. A tumor may be benign (non-cancerous) or malignant (cancerous).

## **U**

### **Ultrasound:**

A test which outlines the shape of specific organs in the body by the use of sound waves rather than x-ray.

## **V**

### **Virus:**

A very small organism that may cause infections. Colds, chicken pox, and measles are all examples of illnesses caused by viruses.

### **Vitamins:**

Nutrients which the body needs to grow and stay strong.

## **W**

### **White Blood Cells (WBC):**

Also called leukocytes. White blood cells are important in fighting infection. Normal white blood cells include: polys, bands, segs, neutrophils, lymphocytes, monocytes, eosinophils, and basophils.

## **X**

### **X-Ray:**

Radiant energy used to diagnose and treat disease.

## **Y**

## **Z**