

St. Jude Children's Research Hospital Family Guide



Patient's Name _____

Patient's St. Jude Identification Number _____

Attending Physician (main doctor) _____

Primary Clinic Nurse (main nurse) _____

Primary Clinic Phone Number _____

Nurse Scheduler (for appointments) _____

When calling from outside Memphis, dial toll-free 1-866-2STJUDE
(1-866-278-5833) for:

Patient Registration (local 901-565-2010)
Travel Office (local 901-565-5000)
Switchboard (local 901-565-3300)
Sickle Cell Program (local 901-565-5670)

Blood Donor Center 595-2024
Child Life Office 595-3020
Clinical Nutrition Office 595-3318
Communications 595-3306
Linda R. Hajar Family Resource Center 595-4639
HelpLine 595-2999
Interpreter Services Office 595-2983
Medicine Room 595-2441
Message Center 595-2305
Patient Services 595-4501 (Meals, travel, lodging)
Pharmacy toll-free 1-866-820-2442 (local 901-565-2113)
Physician Referral Services 595-4055
Security 595-4444
Social Work 595-3670
Volunteer Services 595-3327

The Memphis area code is 901.

Other important numbers

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Mission

The mission of St. Jude Children's Research Hospital is to advance cures, and means of prevention, for pediatric catastrophic diseases through research and treatment.

A Message from the Director

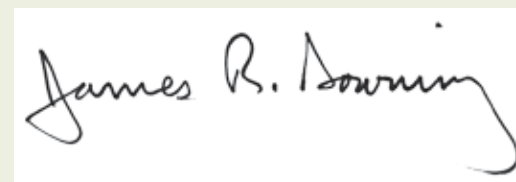
Dear Parents and Caregivers,

We hope this *Family Guide* will be a helpful roadmap for you and your child as you begin the journey through treatment at St. Jude Children's Research Hospital.

In the guide, you will find information that will help you navigate through St. Jude and our housing facilities. In the front of the booklet, you will also find a list of numbers for people to call when you need more details. The St. Jude staff will do everything within their power to answer your questions and provide information you will need during your child's care.

As you get to know St. Jude, the most important thing to remember is that you are not alone. With St. Jude, you have gained a team of some of the most gifted doctors, nurses, and other health care professionals—all united for your child's health, happiness, and well-being.

Sincerely,



James R. Downing, MD
President and Chief Executive Officer
St. Jude Children's Research Hospital



Resources for Learning

If your child becomes a St. Jude patient, this *Family Guide* is the first of many learning materials you will receive. As Dr. Downing says in his letter (page 3), you are an essential part of the patient care team. To be an active partner in your child's care, you will need to learn more about St. Jude, your child's illness, and the proposed treatments.



When you first arrive at St. Jude, you will receive a notebook called the *St. Jude Patient Family Reference Resource*. Please do not feel overwhelmed by the size of this notebook. We do not expect you to read it all right away. Look through the Table of Contents and thumb through the pages to see what it offers. As a St. Jude parent, you can find the answers to many of your questions in the *Patient Family Reference Resource*.

Throughout your time at St. Jude, staff members will offer education sheets to help you understand what is going on with your child's care. The two most common education series are *Do You Know* handouts and *Patient Medication* sheets.

All St. Jude learning materials can be helpful, but please know that the staff will be your greatest resource. Staff members are always happy to answer any questions you might have. We want you to feel that you are part of the St. Jude family. We are here to help you.

1.0 Planning Your Stay

You have just learned that your child might have a life-threatening illness. We know that this is an emotional time for your family. At this moment, packing suitcases for your stay at St. Jude Children's Research Hospital might seem like a low priority. Even so, bringing needed information and familiar items can help provide stability and comfort for you and your child. A checklist is included below. A tear-out copy of this checklist is offered at the back of this booklet. We hope it will make your planning easier. Remember: It may help your child to pack a suitcase of his own with the things that are most important to him. You can follow behind your child and pack the essentials.



1.1 What to bring

- ✓ A government-issued photo identification (ID) card for parent(s) (driver's license, passport, or other official ID)
- ✓ Custody or divorce papers, when needed, to verify who can sign for your child's medical tests and treatments
- ✓ A certified copy of your child's birth certificate
- ✓ Social Security numbers of patient and parent(s) or guardian(s)
- ✓ For patients 18 and older, copies of their advance directives—such as living wills or durable powers of attorney for health care (If you do not have one of these and want to learn more about advanced directives, a St. Jude social worker will give you details about preparing one.)
- ✓ Employer information for the patient, parent(s), or guardian(s)
- ✓ Emergency contact(s) name, address, and phone numbers
- ✓ Insurance information (including medical, pharmacy, and dental insurance cards)
- ✓ Family doctor's name, address, phone, fax, and email address
- ✓ Name of doctor that your insurance company assigned as your child's primary care physician (have address, phone, fax, and email address)
- ✓ Clothing for you and your child to last 7–10 days. Remember: Memphis-area weather might be different than it is where you live. Visit the National Weather Service website to check the Memphis weather forecast (www.nws.noaa.gov).

- ✓ Photographs of family, friends, and pets to help your child cope with feeling homesick
- ✓ A small number of comfort items for your child, such as a blanket or toys (Only smooth-surfaced, easy-to-wash toys are allowed in inpatient rooms. If your child needs a small blanket or cloth toy for comfort, discuss this with your St. Jude doctor. If allowed, these items will need regular washing.)
- ✓ Your child's robe and slippers (if your child becomes an inpatient hospital gowns, toothbrushes, and toothpaste will be provided)
- ✓ Extra supplies of prescription medicines for anyone coming with the patient (Be prepared for an extended stay just in case.)
- ✓ Prescription medicines for the patient

If your trip to St. Jude includes air travel, pack all prescription medicines and important papers in a carry-on bag.

1.2 Safeguarding your possessions

Always remember that you must safeguard your own things. St. Jude is not equipped to store your valuables. Patients and family members should not bring jewelry and other valuables that they cannot keep with them at all times.

1.3 Prevent infection

Many St. Jude patients are at greater risk of infection. Does your child have a rash? Has your child been exposed to chickenpox (varicella) or any infection that could be passed to others, such as a virus or diarrhea? If so, a St. Jude staff member needs to check your child's condition before you allow your child to be near other St. Jude patients. Please call the hospital switchboard at 901-595-3300 and ask for the nursing coordinator. If you are outside the Memphis area, dial toll-free 1-866-2STJUDE (1-866-278-5833). We can arrange:

- ◆ For your child to be seen in one of the clinic isolation rooms;
- ◆ For private transport to the hospital, so other patients are not exposed to an illness that could be spread; and
- ◆ For you to stay in St. Jude housing isolation rooms or a hotel, where your child will not be around other patients.

To learn more about what you should do if your child has an illness that could be passed to others, ask for a copy of the handout "Do you know... ACU isolation to prevent infection."

1.4 Your other children

During your visit to St. Jude, we encourage you to leave other children at home if you can. The St. Jude staff cannot provide care for your other children. We understand that separating a family during such a difficult time is hard, but our goal is to keep all your children safe and healthy. Staff members in Social Work, Psychology, Child Life, and Nursing can offer ideas to help you deal with the needs of your other children. The patient will still need to talk to family members and friends often for comfort and support.

1.5 Help for communication needs

For your child to receive the best care, you must be able to talk with and understand members of the St. Jude staff. You are your child's main caregiver. The information you provide is crucial in helping the St. Jude staff:

- ✓ Learn about your child's health history;
- ✓ Plan your child's treatment; and
- ✓ Monitor your child for changes or needs during clinic visits and hospital stays.

If you have special communication needs, please tell a staff member. We can provide extra help to meet those needs. If you or your child is hearing impaired, we can arrange to have an interpreter for the deaf. If you cannot see well, we can make sure that staff members talk to you about all important information that you might normally receive in writing.

Services for international patients who speak limited English

St. Jude has special phones in patient care areas throughout the hospital to help staff members talk with families who speak limited English. Doctors and nurses can pick up these phones and call an over-the-phone interpreter 24 hours a day. This outside service provides interpreters in more than 100 languages. The staff member and patient can talk to each other face to face using these special phones with an interpreter on the line.

At the hospital, families can request an interpreter in one of these ways:

- ◆ Ask any member of the clinical staff for an interpreter.
- ◆ Call Interpreter Services at 901-595-2983 (if no one is available, leave a recorded message).
- ◆ Leave non-urgent written requests for interpreters at the Welcome Desk in either the Patient Care Center lobby or the Chili's Care Center lobby.

[illegible]

When you arrive at St. Jude, your first stop will be Patient Registration. It is located near the lobby of the Patient Care Center. Here, a staff member will begin your child's medical chart. Please have Social Security numbers for you and your child handy as well as insurance details. If you are divorced or you are not the child's natural parent, you must show that you have custody. Please tell the staff member if your child has had medical records in the past under a different name.

- ◆ Monday through Friday, 6:30 a.m.–10 p.m.; and
- ◆ Saturday and Sunday, 7:30 a.m.–10 p.m.

When Patient Registration is closed, the nursing coordinator will fill out a brief registration. Another staff member will contact you at a later time to complete the needed paperwork.

You will be asked to read and sign a general consent form. This form allows staff members to perform tests to diagnose your child's illness. After test results are received, a St. Jude doctor will meet with you to discuss treatment options. After the doctor has explained the suggested treatment plan, you will be asked to sign other consent forms. These forms say that you agree to have your child enrolled in the study and you agree to the treatment your child will receive. It is very important that you understand all consent forms and proposed treatments. Please ask as many questions as you need to understand all the information that staff members give you.

If your child receives care at an affiliate location, you will also be asked to read and sign consent forms at the affiliate sites.

St. Jude has a research participant advocate for clinical research. This person can help you understand basic rights as they relate to clinical research. The research participant advocate will tell you about the informed consent process that is part of every clinical research project. This person also serves as a liaison with St. Jude doctors and other clinical staff members. If you have questions about research rights, benefits, or

risks, please call 901-595-4644. If you are outside the Memphis area, dial toll-free 1-866-JUDE IRB (1-866-583-3472) and ask for the research participant advocate.

2.4 Payment and charges

No family ever pays St. Jude for anything. Insurance coverage is not needed and is not a factor in accepting patients. If your child is accepted for admission and you do not have insurance, St. Jude will cover all treatment costs. If you have insurance, St. Jude will work with your health insurance and will cover all treatment costs not covered by your insurance. If you do not have insurance or other third-party coverage, you will be referred to our MedAssist office to see if we can find insurance coverage for your child. If you have questions about payment, charges, or insurance, talk with a staff member in Patient Registration.

You can find more details about patient family financial responsibilities in the *Patient Family Reference Resource*.

If you receive care at an affiliate institution, please contact that institution for details about your financial responsibilities.

2.5 Assessment and triage

A nurse will escort you and your child to the Assessment and Triage area from Patient Registration. In this area, a nurse checks your child’s temperature, blood pressure and pulse, as well as height and weight. In many cases, the staff will take blood samples.

2.6 Meeting the clinician

After your child’s assessment and check-in, you will meet with a St. Jude clinician—a doctor, nurse, nurse practitioner, or physician’s assistant.

If you brought any information from your hometown doctor or hospital, it will be reviewed with you at this time. The clinician will ask you and your child more health questions to add to the medical chart. After an exam, the clinician might order tests.

Some tests might be performed the first day you arrive; other tests will be set up during the next few days. The tests are different for each child. The staff will explain all tests to you. Test results are needed to correctly name your child’s disease or condition. The tests also help decide what treatments your child will need. If you have questions, please ask.

2.7 Treatment team

The doctor in charge of your child’s treatment is called the attending physician. This doctor will be part of a treatment team in one of the service areas listed below:

A Clinic	Leukemia/Lymphoma
B Clinic	Stem Cell Transplant
C Clinic	Specialty
D Clinic	Solid Tumor
E Clinic	Neuro-Oncology Clinic
H Clinic	Hematology
Translational Trials Unit (TTU)	After Completion of Therapy (ACT) Clinic, and clinics for Infectious Diseases and Endocrine
Radiation Oncology (RO) Clinic	Radiation Therapy

Each team includes doctors, nurses, physician assistants, nurse practitioners, social workers, pharmacists, dietitians, child life staff, and other specialists needed for the care of your child.

A doctor is always on call for each clinic team. This doctor is here to answer your questions at any time—even nights, weekends, and holidays.

If your child is admitted to an inpatient room, the team members caring for your child could change every few weeks. Your child’s attending physician from your primary clinic might not be part of the inpatient team. Even so, that doctor still takes part in planning your child’s treatment through inpatient rounds and team meetings. Also, you can still talk to that doctor by calling your child’s primary clinic.

If you have questions about your child’s schedule, please call the nurse scheduler in your child’s primary clinic.

If you live near a St. Jude affiliate, your child may be able to receive some or most care through an affiliate doctor and treatment team in your home area. Affiliates are located in Baton Rouge, Louisiana; Huntsville, Alabama; Johnson City, Tennessee; Peoria, Illinois; Shreveport, Louisiana; and Springfield, Missouri.

2.8 UT and Le Bonheur

St. Jude has a close relationship with the University of Tennessee (UT) Medical School and the local children’s hospital, Le Bonheur Children’s

Hospital. Many St. Jude patients will be seen by specialists from Le Bonheur and by UT faculty members. Many of these doctors visit St. Jude on certain days of the week to work with St. Jude patients. In other cases, the patient may need to visit Le Bonheur. While most patient surgeries are done in the St. Jude surgery suites, a few are performed at Le Bonheur. Most often, if a St. Jude patient is admitted to Le Bonheur, one of the UT/Le Bonheur specialists (working with St. Jude staff members) will supervise that child's care.

2.9 Scheduling appointments

After your child has been seen, orders will be placed for your return visits to St. Jude. The nurse scheduler in your child's primary clinic will set up your return visits, print an appointment card, and review that card with you. You should meet with your nurse scheduler at the end of each day to review any needs you may have for your next visit. Also visit the nurse scheduler at the beginning of each day at St. Jude, because schedules can change even overnight. If anything delays the planning of return visits, the nurse scheduler will call you or mail an appointment card to your home address. The nurse schedulers are located in each clinic Monday through Friday, 7:30 a.m.–5 p.m. A nurse scheduler will also be in the Medicine Room each weekday from 5–8 p.m. and on Saturdays, Sundays, and holidays from 7 a.m.–7 p.m.

To schedule an appointment at an affiliate clinic, please call the location during normal working hours. See the list of affiliate clinics, hours of operation and phone numbers below.

Baton Rouge, Louisiana

The St. Jude Baton Rouge Affiliate Clinic at Our Lady of the Lake Children's Hospital (Our Lady of the Lake Regional Medical Center)
Hours of operation: 8 a.m.–4:30 p.m., Phone number: 225-763-6337

Huntsville, Alabama

The St. Jude Huntsville Affiliate Clinic at Huntsville Hospital for Women and Children (Huntsville Hospital)
Hours of operation: 9 a.m.–5 p.m., Phone number: 256-265-5833

Johnson City, Tennessee

The St. Jude Tri-Cities Affiliate Clinic at the Niswonger Children's Hospital (Johnson City Medical Center)
Hours of operation: 8 a.m.–4:30 p.m., Phone number: 423-431-3950

Peoria, Illinois

The Jim and Trudy Maloof St. Jude Midwest Affiliate Clinic at Children's Hospital of Illinois (OSF St. Francis Medical Center)
Hours of operation: 8 a.m.–4:30 p.m., Phone number: 309-624-4945

Shreveport, Louisiana

The St. Jude Shreveport Affiliate Clinic at the Feist-Weiller Cancer Center (Louisiana State University Health Sciences Center)
Hours of operation: 8 a.m.–4:30 p.m., Phone number: 318-813-1100

Springfield, Missouri

The St. Jude Clinic at Mercy Children's Hospital – Springfield (Mercy Hospital – Springfield)
Hours of operation: 8:30 a.m.–5 p.m., Phone number: 417-820-5833

2.10 Focusing on hope

The St. Jude staff believes that hope is essential to life, and that hope can directly influence the well-being of pediatric patients. Hope can help patients make the best of difficult moments and make sense of having a serious illness. Dreams, wishes, and goals point toward today or the future, and hope is what drives those thoughts. Without hope, each day can seem uncertain or even scary. Having hope, for themselves or others, helps children and teens cope with hardships. The St. Jude staff has done extensive research on this subject. Ask for a copy of the handout "Do you know... Focusing on Hope" to learn more.

2.11 When you have a question

The main hospital telephone number is 901-565-3300. If you are outside the Memphis area, dial toll-free 1-866-2STJUDE (1-866-278-5833) and press 0. This number is answered 24 hours a day. A doctor will always be on call to talk to you about your child. In addition, nursing coordinators are always here to help you.

You may call your child's primary clinic weekdays from 8 a.m.–4:30 p.m. When this number is given to you during your first trip to St. Jude, write it on the inside cover of this booklet for easy reference.

[illegible]

St. Jude patients are more likely to get infections because of their illnesses and the treatments they receive. There might be periods during the course of your child's disease when his immune system is not working well. At these times, your child should stay away from people, including relatives, who have illnesses that could spread to other people. One way to do this is to avoid crowds.



People should not visit the hospital if they have colds, the flu, or other illnesses that could spread to others. Remember: If your child has a rash, has been exposed to chickenpox (varicella) or has any infection that could be passed to other patients, the condition needs to be checked before your child gets near other St. Jude patients. In these cases, please call your primary clinic nurse or the nursing coordinator before coming to the hospital.

The best way to prevent infection is to clean your hands well and often using soap and water or an alcohol-based sanitizer. Try to keep everything that comes in contact with your child clean. If your child becomes an inpatient, everyone must wash their hands before entering and leaving the patient room.

A St. Jude staff member will clean the patient room daily. When this staff member comes to clean your child's room, please do not ask that person to return later unless you need to be alone with your child at that time. To reduce dust and keep the room clean, limit the number of items, including toys, that you have in your child's room. A build-up of clutter could prevent thorough cleaning of the room.

Only smooth-surfaced, easy-to-wash toys are allowed in inpatient rooms. If your child needs a small blanket or cloth toy for comfort, discuss this with the doctor. If allowed, the item will need regular washing. No flowers, plants, or standing water are allowed in patient rooms because of the bacteria and fungi that grow in them.

The air in the hospital is filtered to keep it as clean as possible. In inpatient rooms, we position the beds to give your child the most filtered air. Please do not move your child's bed.

Some vaccines are made from live viruses. Currently, these include oral polio, smallpox, chickenpox (varicella), and MMR (measles, mumps, and rubella) vaccines. These vaccines may pose a threat to your child's

health. Any person with a weakened immune system, including patients with cancer or HIV infection should not receive live virus vaccines unless instructed to do so by a doctor. Do not allow people to visit your child if:

- ◆ They have received oral polio or smallpox vaccines within 4 weeks; or
- ◆ They have rashes after receiving the chickenpox (varicella) vaccine.

3.2 Inpatient visiting guidelines

St. Jude staff members understand that love and support from family and friends help your child adjust to being in the hospital. Even so, we need you to follow the hospital’s visiting guidelines to protect the health and the safety of your child and all St. Jude patients. The following is a shortened version of the visiting guidelines. For a more complete list, please see section 3 of the *Patient Family Reference Resource*. You can also ask a staff member for a handout called “Do you know... Visiting guidelines.”

- ◆ Parents or primary caregivers may stay with their children 24 hours a day, because they are not considered visitors.
- ◆ Many St. Jude patients have weak immune systems. Visitors should not enter the hospital if they are sick or have been exposed to illnesses that are easy to spread (contagious).
- ◆ Please follow all posted guidelines for using masks, gowns, and gloves.
- ◆ Clean your hands each time you enter and leave a patient room.
- ◆ The number of parents and other visitors must be limited to 3 for the Hematology-Oncology Inpatient Unit and 2 in the Intensive Care Unit (ICU), the Transplant Unit, and the Ambulatory Care Unit (ACU). The air cleaning system can do a better job when fewer people are in the room.
- ◆ Many patients make friends at St. Jude; however, for the health of each patient, inpatients should not visit other inpatient rooms. Also, outpatients should not visit the inpatient units.
- ◆ Only one (1) caregiver at a time may stay overnight in the patient room. This person can be a sibling, age 15 or older. Siblings younger than 15 may stay overnight in the parent room if the parent is present.
- ◆ For your child’s safety and your comfort, you may not sleep on the floor.
- ◆ Friends and family members 7 years old and older may visit your child without restriction. Children younger than 7 must be screened daily for illnesses that could pass from one person to another (contagious).

Please talk to your doctor or nurse if you think it is important for someone younger than one (1) year of age to be with your child.

3.3 Food safety

You may eat your meals in the hospital room with your child, but opened food must be thrown out after one (1) hour in a patient room. After that amount of time, bacteria that could be harmful to your child can grow on the food.

Food cannot be stored in your child’s room. Food attracts insects that can transmit disease.

The staff will tell you if your child is on a special diet or can eat food prepared outside the hospital. Food prepared outside the hospital and brought to your child’s room should be stored in the Nutrition Center refrigerator on each floor. Write your child’s name and the current date on each food item container. **Unused food will be removed every 3 days** or right away if it is spoiled.

[illegible]

4.1 Patient Services

Patient Services assists families with transportation, lodging, and meals. When Patient Services is closed, staff members in Patient Registration or Security can help you with transportation and lodging. Please request meal cards during regular office hours.

You should direct all questions about St. Jude policies for help with patient travel, lodging, and meals to Patient Services. This department is located on the plaza (basement) level of the Patient Care Center.

Patient Services office hours

- 🕒 Monday through Friday, 7 a.m.–6 p.m.
- 🕒 Closed on Saturdays, Sundays, and these holidays: New Year's Day, Martin Luther King Jr. Day, Memorial Day, July 4th, Labor Day, Thanksgiving, and Christmas

Patient Services: 901-565-4501

Patient Registration: 901-565-2010

Security: 901-565-4444

From outside Memphis, dial toll-free 1-866-2STJUDE (1-866-278-5833) and the last four digits of the department you are calling.

If you need patient services at the affiliate, please call the affiliate during normal office hours. See the list of telephone numbers and office hours in section 2.9.

4.2 Travel

After your child is accepted as a patient, St. Jude offers help with travel plans and costs for the patient and one (1) parent or guardian for planned treatments and checkups. If you live more than 35 miles and less than 300 miles from St. Jude, the hospital will arrange bus or rail travel for you, or pay for auto mileage. If you live more than 300 miles from St. Jude, the hospital will arrange bus, rail, or air travel or cover the cost of auto mileage or a rental car. Except for auto mileage, you must request all help with travel (plans and costs) in advance. After your child's first visit to St. Jude, you should arrange domestic air travel 14 days before you need to arrive in Memphis or as soon as you receive your child's next appointment schedule.

International flights must be requested at least 60 days before your child’s next appointment. St. Jude will also cover the cost of standard airline baggage charges.

✈ To make air travel or rental car reservations, call the St. Jude Travel Office. If you are outside the Memphis area, dial toll-free 1-866-278-5833, and press 3#. If you are in the local area, call 901-565-5000. After the first visit, the St. Jude Travel Office should make all air travel and rental car reservations.

🚌 To schedule bus, rail, or local transportation, call Patient Services. If you are outside the Memphis area, dial toll-free 1-866-278-5833 and enter extension 4501. For local calls, dial 901-565-4501. After the first visit, the St. Jude Patient Services office should schedule all bus or rail travel.

4.3 Airport shuttle

Patient Services arranges shuttle service to and from Memphis International Airport. This service is offered at no cost to the patient and one (1) parent. Tennessee Carriers provides the airport shuttle service for St. Jude. This service operates 7 days a week from 6 a.m.–9:30 p.m.

The Travel Office staff will automatically schedule shuttle service from the airport to St. Jude when they process your airline tickets. Tennessee Carriers will be waiting for you in the Delta baggage claim area near the escalator. The driver will hold a sign that reads “St. Jude Family Pickup.” If the driver is not there when you arrive, please wait at least 20 minutes. Then, call 901-565-4501.

Requests for shuttle service to the airport must be made at least one (1) day in advance. To arrange this service, call Patient Services at 901-565-4501. If you are in the hospital, dial extension 4501. If you are outside the Memphis area, call toll-free 1-866-2STJUDE (1-866-278-5833) and dial 4501 when the call connects. You may call Patient Services Monday–Friday 7 a.m.–6 p.m.

4.4 Where to stay

St. Jude provides free lodging to patient families who live more than 35 miles from the hospital when the patient’s treatment requires an overnight stay. If you live less than 35 miles from St. Jude, you will return home between clinic visits.

If you live more than 35 miles from Memphis, your stay will be arranged at one (1) of these St. Jude-sponsored lodging facilities:

- 🏠 **Short-Term Lodging Facility:** Tri Delta Place is located on campus near the hospital. It is reserved for St. Jude patients and families who need lodging for 1–7 days.
- 🏠 **Mid-Term Lodging Facility:** The Ronald McDonald House is for St. Jude patients and families who need lodging for 8–90 days.
- 🏠 **Long-Term Lodging Facility:** St. Jude patients and families who need lodging for 90 days or more will be assigned to Target House.

After your child’s first visit to St. Jude, you must call in advance to reserve housing space. As soon as you receive your child’s next appointment schedule, call Patient Services to reserve lodging. Housing placements are based on length of stay and medical needs. St. Jude will not pay for your long distance telephone service or entertainment while you stay in St. Jude-sponsored lodging. Please respect these accommodations (building and contents) as you would your own home.

St. Jude provides lodging for the patient and one (1) parent or guardian in each St. Jude-sponsored room or apartment. Through the generosity of our donors, each room and apartment is designed to house up to 4 people but no more than 4. If the rooms become too crowded, the risk of infection increases for your child and other patients staying in these facilities. In addition, the shuttle buses could become overloaded, and the hospital would have to pay more for supplies, upkeep, and utilities.

Because all families deserve equal treatment, St. Jude cannot grant exceptions to these lodging rules. The rules are the same for all St. Jude housing facilities. If you have more than 4 family members coming into town, please arrange for them to stay somewhere other than St. Jude housing. Patient Services can give you a list of local hotels that offer below-market rates to St. Jude families who need more rooms.

If you have questions about St. Jude housing guidelines, call Patient Services at 901-565-4501 or talk with your social worker. If you are inside the hospital, dial 4501. Outside the Memphis area, call toll-free 1-866-2STJUDE (1-866-278-5833). After the call is connected, enter extension 4501 for Patient Services or 3670 for Social Work.

4.5 Hospital shuttle buses

Hospital shuttle buses will take you back and forth between St. Jude and the Ronald McDonald House, Target House, Tri Delta Place, or your hotel. You are not charged for this service.

The shuttle buses run a continuous loop as noted on schedules available at each housing facility, the Patient Care Center and Chili's Care Center information desks.

For special transport requests, including early pick-up or after-hours emergency transport, call Security at 901-595-4444.

Since the shuttles follow a set route, drivers cannot honor requests for side trips to restaurants and other locations. Some shuttle buses make periodic trips to a local grocery store and drugstore that have been selected and approved by the hospital. Ask about this service at your housing facility.

If you have called for a special pick-up, please meet the shuttle at the correct time and place. This will ensure prompt service for others. Also, we ask that you follow these rules:

- 🚗 No smoking, eating, or drinking on the shuttle buses.
- 🚗 Food and drink should be in sealed containers to prevent spills.
- 🚗 Seat belts must be worn at all times.
- 🚗 Children 3 years old and younger must ride in child restraint seats. Children 4 to 8 years old must be in booster seats if they are less than 5 feet tall. These are Tennessee state laws with no exceptions. Parents who do not put their children in safety seats will not be able to use the hospital shuttles. Child safety seats are offered on all shuttles.
- 🚗 Children under the age of 16 must be with an adult when riding the shuttle bus.

4.6 Meals

St. Jude offers help with the cost of meals for the patient and one (1) caregiver by issuing a St. Jude meal card or a grocery store gift card.

Meal cards are activated for the number of days and meals for which the patient is eligible. The card can be programmed for up to 7 days in a row. The meal card is programmed for specific dollar amounts and time periods. These amounts and times depend on the type of meals requested—breakfast, lunch, or dinner—and on the patient’s status—inpatient or outpatient.

Patient families should request their meal cards from Patient Services upon arriving at St. Jude. Patient Registration can also issue meal cards and activate them when Patient Services is not open. If your meal card expires, it must be reactivated in one of these departments. You can use the meal card at the hospital cafeteria for all meals. However, St. Jude meal cards cannot be used off campus.

When families check in at Tri Delta Place, their meal cards will be activated to serve as room keys, as well. When issued, 2 meal cards are programmed so each family will have 2 room keys. The meal cards are reusable, so please deposit your inactive meal cards at the front desk when checking out of Tri Delta Place. You can also place your used, inactive meal cards in the cafeteria drop box or in the drop box at the Patient Services window.

St. Jude provides grocery store gift cards to patient families staying at the Ronald McDonald House or Target House. Parents can request the grocery store gift cards weekly in Patient Services, Monday through Friday 9 a.m.–3:30 p.m. A family’s weekly allotment of gift cards may vary depending on where the patient is staying. A parent at the Ronald McDonald House or Target House may choose to receive a St. Jude meal card instead of a grocery store gift card if the patient becomes an inpatient. If the patient’s status changes in the middle of the week, the meal card can be traded for a grocery store gift card.

Local patients and those staying in short-term lodging are not eligible for grocery store gift cards.

4.7 Where to eat

The hospital cafeteria, called the Kay Kafe, is on the first floor of the Richard C. Shadyac ALSAC Tower, which is the building next to and connected to the Patient Care Center. The main hallway on the north side of the Patient Care Center will lead you to the cafeteria. Just before you reach the cafeteria, you will see an automatic teller machine (ATM) for your convenience.

St. Jude Cafeteria hours

Monday through Friday

Kafe is open 7 a.m. –7 p.m. Grill is open 11 a.m.–7 p.m.

Weekend and Holidays

Breakfast: 7:30–11 a.m. (Hot food line closes at 10 a.m.).

Lunch and Dinner: Grill is open 11 a.m.–7 p.m.

Please note: The cafeteria can only accept cash, St. Jude meal cards, MasterCard and Visa.

To call Food Service, dial 901-595-3307.

4.8 Snack bags

Snack bags are offered free for outpatients while at St. Jude for treatment. You may pick up a snack bag ticket in the Patient Services office each day your child is on campus for treatment. You can then pick up the snack bags in the cafeteria from 7 a.m.–7 p.m., Monday–Friday. Each snack bag contains 4 nutritional snack items including a drink.

4.9 Registered dietitians

Registered dietitians are here to offer you advice and ideas about your child’s nutrition needs. They can also help you with food-related problems. You can reach the dietitian for your primary clinic by calling the Clinical Nutrition office at 901-565-3318.

4.10 Luggage

You must guard your own clothing and valuables. St. Jude cannot be responsible for items lost or stolen. Please do not bring valuables with you, such as jewelry and large amounts of cash, when you are staying at the hospital or in St. Jude-sponsored housing. To help you, St. Jude offers a luggage checkroom in the Patient Care Center first floor lobby. The security officer at the information desk in the PCC lobby has a key to the luggage room.

4.11 Laundry and showers

Washers and dryers are located on the second floor of the Patient Care Center. The laundry rooms also contain showers for use by parents whose children are inpatients. These rooms are open 24 hours a day. St. Jude is not responsible for laundry and other items left unattended. Laundry detergent is provided free of charge.

4.12 Telephones

Cell phones, Blackberry™ devices, and two-way radios can cause problems with machines used to treat your child. For the safety of all St. Jude patients, you must turn off these devices before entering the Intensive Care Unit (ICU) patient rooms and the operating rooms on the third floor of the Patient Care Center. See section “7.1, Cell phones, two-way radios, etc.”

The Patient Care Center has many courtesy telephones for making local and collect calls. They are located on each floor, including the plaza level near the doors to the underground parking area. Dial 9 to get an outside line.

All inpatient rooms have telephones that can be used for making local calls. Dial 9, plus the number. Credit card or collect calls may be made from these phones by dialing 117+00+area code+number. The operator will come on the line to help.

4.13 Check cashing/automatic teller machine (ATM)

You will not be able to cash personal checks in Memphis without having an account at a Memphis bank. You should take money orders, cashier’s checks, and Social Security checks to the Patient Services office on the plaza level of the Patient Care Center, where a staff member can stamp them: “This item has been approved for cashing by St. Jude Children’s Research Hospital.” After being stamped and signed by a Patient Services staff member, the item can be cashed with proper identification at First Tennessee Bank’s downtown branch, 165 Madison Ave. On a case-by-case basis, the First South Credit Union office on the plaza level of the Patient Care Center will cash Social Security checks, checks issued by St. Jude and checks issued by cancer-care organizations. First South requires that the name on the check exactly match your personal identification card. You should not sign your check or money order until you get to the bank or credit union.

An automatic teller machine (ATM) for withdrawing cash is located just outside the cafeteria on the first floor of the Richard C. Shadyac ALSAC Tower.

4.14 Mail

Mail and packages may be picked up in Patient Services (BP-004) on the plaza level of the Patient Care Center Monday through Friday, 10:30–11:30 a.m. and 3–4 p.m. Friends and family may send mail for patients to the address below:

Patient’s name
St. Jude Children’s Research Hospital
262 Danny Thomas Place
Memphis, TN 38105-3678

U.S. Postal Service (USPS) has a drop box located outside near the south entrance to the Danny Thomas Research Center. You may leave stamped addressed letters to be picked up by a mail carrier at either of the front lobby message centers. If you have packages to send, please take them to the St. Jude Mail Service Center in the 505 Building (south entrance). You can send your packages and letters at regular postal rates. We can also offer you discounted FedEx rates.

[illegible]

5.1 Nurse schedulers

A stylized illustration in a light green color. It depicts a doctor, represented by a circle with a cross (a medical symbol), standing and leaning over a small child. The child is sitting on a small stool. The doctor is holding a stethoscope to the child's back, examining them.

5.2 Outpatient care

Patients from affiliate areas may also receive outpatient care at the affiliate sites.

5.3 A routine clinic visit

The usual steps of your day are:

- ✓ Registration desk;
- ✓ Assessment and Triage;
- ✓ Patient representative;
- ✓ Check-up by a member of your clinical team;
- ✓ Treatment; and
- ✓ Nurse scheduler to help plan your next visit.

Other steps may include:

- ✓ Special testing, such as X-rays, CT, or MRI;
- ✓ Pharmacy to pick up prescriptions and medicine counseling;
- ✓ Meeting with psychologist, social worker, chaplain, or child life specialist;
- ✓ School lessons in one of the hospital classrooms;
- ✓ Food and nutrition counseling; and
- ✓ Dental or other specialty clinic visit.

5.4 Inpatient care

If the doctor decides your child needs to stay in the hospital or needs surgery, your child will be admitted to one of the hospital's inpatient rooms. The Patient Care Center second floor houses the Hematology-Oncology Inpatient Unit. The Intensive Care Unit and Surgical Services are on the second floor of the Kay Research and Care Center, and the Transplant Unit is on the second floor of the Chili's Care Center. Each floor has isolation rooms for patients who have or might have an illness that could be spread to other patients.

Every St. Jude inpatient room has an attached parent room with a window for viewing the patient room. The parent room allows you to rest while still keeping an eye on your child. The parent rooms are not designed for long-term stay. Please keep them free of clutter so they can be cleaned well.

Patients from affiliate areas may also receive inpatient care at the affiliate sites.

5.5 Social workers, psychologists, chaplains

Shortly after you arrive at St. Jude, a social worker will meet with you to help you get settled. The Social Work staff can support you and your family by offering counseling, parent and patient support groups, therapeutic play, and information about referrals to services within the hospital and your home community. Check with your social worker to learn about current patient and family groups that are offered. The Social Work staff can also provide information about financial resources, wish-granting groups, and other community services to address needs that you or your treatment team identify. If you need to talk to your social worker when you come to the hospital, have the patient representative call or page the social worker for you.

Psychology staff members provide therapy and support to patients and their family members. Psychologists can help patients and families:

- ✓ Manage stress;
- ✓ Address feelings of anxiety, anger, depression, fear, grief;
- ✓ Find ways to cope;
- ✓ Manage discipline and behavior problems;
- ✓ Resolve conflicts in relationships (parent-child or family member-family member);
- ✓ Manage pain;
- ✓ Solve or improve learning problems; and
- ✓ Work on self-esteem issues.

Ordained ministers serve as chaplains at St. Jude. Upon your request, they can provide spiritual support, counseling, and sacraments. They are here to help you as spiritual friends. They are not here to judge you or change what you believe. Their goal is to meet you where you are and to help you explore how your faith can be a source of strength and comfort to you.

If you need to speak with a social worker, chaplain, or psychologist, ask any staff member or the nursing coordinator to help you.

5.6 Child Life

Child life specialists are here to help your child—and the entire family—cope with the stress and anxiety of facing a life-threatening illness.

Child Life most often uses play when working with patients, because play is a natural outlet for a child's creative energy. Through play, art, and other activities, the Child Life staff gives children and teens facts about their diseases and treatments. These activities help patients express their feelings about being in the hospital. In this way, the Child Life staff dispels myths and promotes understanding. Many of these activities help patients and family members talk out their fears and concerns. Child Life offers these services for patients, brothers, sisters, and other family members.

Child Life staff members also operate all the hospital play areas as well as the Teen Room and Pre-Teen Room. Learn more about Child Life services in section 4 of the *Patient Family Reference Resource*.

5.7 School Program

School is a normal activity for children and teens. For young patients, school can offer a familiar and reassuring routine. It also can help them feel in step with the outside world. School allows children and teens to remember who they are and to hope for the future. The St. Jude School Program is accredited as a Special Purpose School by the Southern Association of Colleges and Schools.

The St. Jude School Program offers:

- 📖 Hospital-bound services and homebound services;
- 📖 School re-entry services; and
- 📖 Advocacy services.

To learn more about the School Program and services offered, call 901-595-3346. If you are inside the hospital, dial 3346. If you are outside the Memphis area, call 1-866-2STJUDE (1-866-278-5833) extension 3346.

5.8 St. Jude Domestic Affiliate Program

St. Jude has partnered with institutions (see section 2.9) in six cities in the central United States. These affiliates allow patients to receive care at home. They help expand the number of children receiving St. Jude services and ease financial and other burdens on these patient families. Affiliates also help increase the number of children on St. Jude protocols to help find cures faster and save more children. The staff at the affiliate clinics are employees of the affiliate institutions and follow the policies of those hospitals. St. Jude audits and monitors the care that is provided by the affiliates to ensure that good quality of care is delivered and that the affiliates follow St. Jude research protocols and national standards. If you have questions about an affiliate, you may contact that clinic directly or the St. Jude Domestic Affiliate office at 901-595-3277. (See the list of locations, institutions, office hours, and telephone numbers in section 2.9.)

Notes

6.0 Things to Remember

6.1 Correct info needed

It is important that we have correct contact information for your family. For this reason, the Patient Registration staff will ask you for updates to your child's medical record at least every 60 days.



Please report any changes to these items as soon as you can:

- ✓ Address (home or work)
- ✓ Telephone numbers (home, work, cell, or pager)
- ✓ Employer
- ✓ Insurance coverage
- ✓ Doctor(s) at home (when your child has a new doctor at home or if a home doctor's contact information changes)
- ✓ Any changes in patient custody
- ✓ Marital status of patient or parents/guardians

To report changes to this information, call Patient Registration at 901-595-2010. If you are outside the Memphis area, dial toll-free 1-866-2STJUDE (1-866-278-5833), and press 2# when the call connects. If you sign the proper release form in Patient Registration, we can accept your changes by email. After you sign the "Consent to Communicate Via Email" form, you can send information changes to PatientInfoUpdate@stjude.org. We also can accept your changes by fax if you call Patient Registration first. Then, mark each page "Confidential" and fax to 901-595-3088.

6.2 Free notary services

St. Jude offers notary services free of charge for St. Jude related forms and for the personal needs of patient families. Several staff members in Patient Registration and in the Linda R. Hajar Family Resource Center are notaries. To find a notary at St. Jude, please talk to the guest services representative at the Patient Care Center lobby information desk.

6.3 Guest services representative

A guest services representative sits in the lobby of the Patient Care Center and Chili's Care Center Monday through Friday 7:30 a.m.–4 p.m. This person can help patient families in many ways:

- ✓ Take messages for patients and patient families (see section 6.4 Message center)
- ✓ Provide housing information for out-of-town family members
- ✓ Help locate patients and family members in the hospital
- ✓ Give donation information and take donations for St. Jude
- ✓ Accept deliveries for patients
- ✓ Provide waiting room activities for patients and siblings
- ✓ Help families arrange hospital tours
- ✓ Hand out a list of Memphis-area activities that are discounted or free for St. Jude patients
- ✓ Announce special events over the intercom
- ✓ Accept stamped, addressed letters to be mailed by the USPS
- ✓ Answer questions such as:
 - ? Who is my social worker?
 - ? Am I scheduled for Tennessee Carriers pick up?
 - ? What is the shuttle bus service?
 - ? How do I locate an interpreter?

6.4 Message center

Family and friends from home may leave telephone messages at one of the message centers (Welcome Desks) in the Patient Care Center or Chili's Care Center lobbies. The telephone number for the Patient Care Center message center is 901-595-2305; from outside Memphis, dial toll-free 1-866-2STJUDE (1-866-278-5833). Then, dial 2305 when the call connects. The telephone number for the Chili's Care Center message center is 901-595-8605. If you are outside Memphis, dial the toll-free number above and then extension 8605 when the call connects. At night and on weekends, staff members in Patient Registration can assist with relaying messages to patients and parents from 4–10 p.m. In emergencies, the nursing coordinator on duty may also help with relaying messages. The staff cannot give out private information about you or your child in these messages.

6.5 Pharmacy

If you are taking prescription medicine, remember to bring an extra supply on your trip to St. Jude just in case your stay becomes longer than you expected. The St. Jude Pharmacy is for patients only. St. Jude cannot provide medicine for other family members.

Pharmacy hours

- ◆ Pharmacy (Patient Care Center first floor) – Monday through Friday, 8:30 a.m.–6 p.m. After 6 p.m., or on holidays and weekends, you may pick up outpatient medicines by ringing the bell beside the Pharmacy pick-up windows. After 11 p.m. you will need to ring the bell and then pick up medicines in the pharmacy counseling room right next to the pick-up windows.
- ◆ Translational Trials Unit (TTU) Pharmacy – Monday through Friday, 8:30 a.m.–5 p.m. (for patients treated in the TTU) To pick-up prescriptions after 5 p.m., you will need to go to the Pharmacy located in the Patient Care Center, first floor.

To find out more about Pharmacy Services, call 901-565-2298. If you are outside the Memphis area, dial toll-free 1-866-2STJUDE (1-866-278-5833), extension 2298.

6.6 Linda R. Hajar Family Resource Center

The Linda R. Hajar Family Resource Center is open 24 hours a day. It offers computers, books, Internet access, a copier, fax machine, and comfortable study and reading areas. It also provides fun reading materials, reliable medical information, and general library services to patients and family members. You can check out a variety of materials, including current magazines, paperbacks, CDs and DVDs. Reference books are offered, as well. The facility is located on the second floor of the Patient Care Center. To learn more about the Family Resource Center, call 901-565-4639.

6.7 For your safety

Guest safety tips are included in section 11 of the *Patient Family Reference Resource*. The safety information offers ideas for protecting yourself, your child, and your personal possessions during your stay in Memphis. If you have safety concerns or problems while you are at St. Jude, call Security at extension 4444.

6.8 Gift shops

You will find the hospital gift shop next to the Patient Care Center lobby. The gift shop is open Monday through Friday 8:30 a.m.–4 p.m. The shop sells a variety of items for all ages, including toys, stationery, candy, and gifts. If you forgot any personal care items from home, check the hospital gift shop.

St. Jude souvenir items can be found in the ALSAC Gift Shop, which is outside the hospital next to the Danny Thomas/ALSAC Pavilion. The ALSAC Gift Shop hours are 8:30 a.m.–4:30 p.m., Monday–Friday.

6.9 Chapel

A nondenominational chapel is located on the first floor of the Patient Care Center (near the south waiting area). It is open 24 hours a day for personal meditation. If you need to speak with a hospital chaplain, call the Chaplain Services office at 901-565-3672. Chaplains can help you find worship opportunities in the Memphis area to meet your spiritual needs.

6.10 Blood Donor Center

The Blood Donor Center, located on the first floor of the Patient Care Center, collects platelets and other blood products needed for the care of children treated at St. Jude. The center is an easy place for families and friends to donate blood products. All products collected in the Blood Donor Center go directly to St. Jude patients. The center is open daily from 7:45 a.m.–6 p.m. except for Tuesday when the center opens at 9:15 a.m. If you would like to donate platelets or whole blood, please call the Blood Donor Center at 901-595-2024 or stop by for an appointment.

Notes

7.0 Important Policies

7.1 Cell phones, two-way radios, etc.

Cellular phones, BlackBerry™ devices, and two-way radios (walkie-talkies) can cause problems with medical equipment. This includes camera phones. Signals from the phones, radios, and other devices can cause some critical machines to stop working or not work the right way. Machines used in the Intensive Care Unit (ICU) and Surgery are the most sensitive.

Do not risk harming your child or another patient. Please remember to turn off cell phones, two-way radios, and blackberry devices before entering the ICU patient rooms and the Surgery suites on the third floor of the Patient Care Center.

7.2 Patient and visitor parking

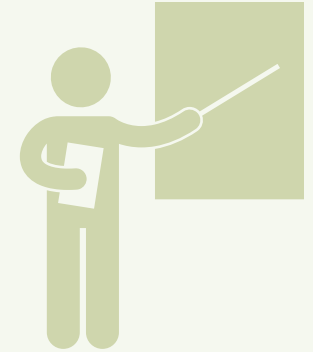
Security issues parking hangtags and instructions at the information desk in the Patient Care Center. When your vehicle is on the St. Jude campus, you must display parking hangtags where security officers can see them.

Parking is prohibited in the blood donor and pavilion parking lots, fire lanes, and other restricted areas. These areas are clearly marked. Violations of parking policies could lead to parking tickets, towing, or loss of St. Jude campus parking privileges.

Limited outpatient parking is offered in the Patient Care Center underground garage. You can enter this garage from the main gate (Gate 1) on Lauderdale Street. This parking is monitored 24 hours a day from the Security control center. Overflow outpatient parking is sent to the patient and visitor parking area located between the Barry building and the Chili's Care Center. More overflow patient parking includes Tri Delta Place parking lot.

You can enter the regular patient and visitor parking area from the intersection of Third Street and Overton (Gate 2) where these security measures are in place for your safety:

🚗 A gated and fenced parking area has a 24-hour, guard booth security officer and roving patrol. Patients and families are strongly encouraged to use this lot instead of parking on Jackson Avenue or Third Street, where there is no security.



- 🚌 St. Jude operates several shuttle buses every day of the week. Pick up a shuttle bus schedule at your housing facility or at the information desk in the Patient Care Center or Chili's Care Center. Shuttle buses provide car-side service for patients and visitors. One of the shuttle buses has a wheelchair lift. (After hours, call Security at extension 4444 for transport.)

Parking and shuttle reminders

- 🚗 Please park head-in only in the underground garage. Do not back into parking spaces.
- 🚗 Do not park in reserved or designated spaces or areas. They are marked with signs.
- 🚗 Make sure you have all your belongings when leaving the shuttle bus.
- 🚗 Report any accidents or thefts to Security at extension 4444.

7.3 Smoking

St. Jude is a smoke-free institution. No one can smoke in a St. Jude building under any condition, and no patient under the age of 18 is ever allowed to smoke. Smoking is allowed only in these marked areas outside the hospital:

- ◆ Across the street from the south side of the Richard C. Shadyac ALSAC Tower, which is the building directly east of and connected to the Patient Care Center.
- ◆ Outside Tri Delta Place near the southeast end of the building.

Please respect those who do not smoke. If you must smoke, be careful to do so in marked areas only. Smoking, including passive smoking, is harmful to your health and our patients' health. Smoking rules are strictly enforced. Please do not expose your children to smoking.

7.4 No alcohol or drugs

St. Jude is an alcohol-free and drug-free campus. Anyone with alcohol or under the influence of alcohol will be required to leave the campus. For the safety of our patients, families, and employees, the St. Jude staff has the right to remove anyone who is impaired by alcohol or drugs.

7.5 No harassment

St. Jude Children's Research Hospital will not permit or condone any form of harassment based on age, race, color, national origin, religion, sex, gender identity, gender expression, sexual orientation, or disability. If you or any member of your family feels harassed by a St. Jude employee or another patient family, please report this problem to the nursing coordinator. Call the hospital switchboard at 901-595-3300, and ask for the nursing coordinator.

7.6 No weapons allowed

Please remember that weapons are not allowed at any St. Jude facility. In addition to the hospital, weapons are prohibited at Target House, Ronald McDonald House, and Tri Delta Place. The rule against weapons includes everyone—even people who are licensed to carry weapons. The only exception is for licensed law enforcement officers.

7.7 Media visits

If a reporter or photographer wants to come to St. Jude to do a story about you or your child, please call the hospital's Communications department right away. A Communications representative must be with members of the media at all times while they are on the grounds of the hospital and its housing facilities. Before you make media arrangements, please call or email Communications at 901-565-3306 or media@stjude.org. If you are at the hospital, dial extension 3306. If outside the Memphis area, call 1-866-278-5833 extension 3306.

At times, you may be asked to speak to the media. If you agree to do so, you will be asked to sign a release form.

[illegible]

As a patient of St. Jude Children's Research Hospital, I have the right:

- ◆ To not be discriminated against on the basis of age, race, ethnicity, religion, culture, language, physical or mental disability, socioeconomic status, sex, sexual orientation, and gender identity or expression.
- ◆ To know the names of the doctors, nurses, and others who take care of me.
- ◆ To be treated with courtesy and respect.
- ◆ To be comfortable, nourished, and without restraints whenever possible.
- ◆ To have the staff assess and manage my pain properly.
- ◆ To receive care in a safe setting.
- ◆ To choose whether or not to receive visitors, and which visitors to receive, following St. Jude visiting rules that might limit some visits or visitors for medical reasons.
- ◆ To have all my questions answered in words I understand.
- ◆ To have an interpreter for me or my family whenever needed, if at all possible.
- ◆ To privacy in treatment and to confidential medical records, according to laws that govern privacy and medical records.
- ◆ To be given information that will help me take care of myself upon discharge.
- ◆ To be free from any form of abuse, neglect, or harassment.
- ◆ To be involved in the decision making for all aspects of my care. This includes the right to refuse treatment and the right to refuse to consent to take part in research.
- ◆ To create an advance directive, if I am an adult, and to receive more information about advance directives if desired.
- ◆ To express a concern or ask a question about my care and to have my concerns addressed.

8.2 Patient responsibilities

As a patient at St. Jude Children's Research Hospital, I have the responsibility:

- ◆ To pay attention to changes in my body and how I feel and tell the staff so they will know, too.
- ◆ To ask questions if I do not understand something that is being done for me or not done for me, including any changes in my care plan.
- ◆ To cooperate with the hospital staff in my treatment and tell them what they need to know to take care of me.
- ◆ To let the staff know anything that I am taking in addition to the medicines I get at St. Jude.
- ◆ To follow the hospital rules as they have been told to me and ask for help when I do not understand them.
- ◆ To take part in my treatment-related care and ask questions when I do not understand.
- ◆ To be polite and thoughtful about other people's needs to be alone, have privacy, and have quiet time.
- ◆ To be considerate and respectful of other patients and staff.
- ◆ To cry or show my feelings in a way that helps me and does not hurt others.
- ◆ To let the staff or someone know if I feel abused, neglected, harassed, unsafe, or have experienced incorrect behavior.

8.3 Patient and family concerns

St. Jude is dedicated to safe, effective, quality patient care. To continue to improve, staff members need to hear your thoughts about the care your child receives. Please share your ideas, comments, and concerns in any of the following ways.

For urgent concerns about your child's health as an inpatient:

If your child is a St. Jude inpatient, the St. Jude Rapid Response Team (RRT) is a team of staff members dedicated to responding quickly when urgent medical help is needed at the hospital. If you or your nurse or doctor is concerned about your child's current medical state, the RRT will arrive quickly to check on your child. Please talk to the staff first about your concerns. But if you feel the RRT needs to be called, you are welcome to do so by dialing 3999 from any hospital phone. From a cell phone, dial 901-595-3999.

For urgent concerns about your child's health as while away from St. Jude:

If you are away from St. Jude and you have urgent concerns about your child's health or well-being, go to the nearest hospital emergency department or dial 911.

For all other concerns about your child's medical care:

- ◆ Talk to a member of the health care team.
- ◆ Talk to the nursing coordinator. This staff member wants to help you as soon as you notice a patient care concern. Call the hospital switchboard at 901-595-3300 and ask for the nursing coordinator (one is on duty at all times).

For concerns about specific departments or services not related to your child's medical care:

- ◆ Talk directly to the department involved.

For a patient care concern or other concern that has not been resolved:

If the health care team and the nursing coordinator have not resolved your concerns, you may call the St. Jude HelpLine at any time, 24 hours a day. If you are inside the hospital, dial 2999. Outside the hospital, call 901-595-2999. A staff member answers the HelpLine Monday through Friday, 8 a.m.–4:30 p.m. After hours, please leave a message so we can return your call the next business day.

For concerns about possible abuse or neglect:

- ◆ Reach the Patient Abuse Officer 24 hours a day, 7 days a week by calling the hospital switchboard at 901-595-3300.

To share ideas or comments with staff or other parents:

- ◆ Talk directly with staff members.
- ◆ Fill out and return a Patient Satisfaction Survey. You may receive a survey by mail after an inpatient visit. These surveys help us improve care for all St. Jude patients.
- ◆ Read the *St. Jude Parents* newsletter and send the editors questions and ideas for future articles.

Contacting an outside agency

St. Jude is committed to upholding the standards of The Joint Commission. The Joint Commission sets the standards by which health care quality and safety are measured in the United States and beyond.

If you would like information about those standards or have a concern about patient safety, you can talk to The Joint Commission Coordinator at St. Jude by calling 901-595-4684.

You can contact The Joint Commission directly at:

The Joint Commission
One Renaissance Blvd. Oakbrook Terrace, IL 60181
630-792-5000 www.jointcommission.org
Email: complaint@jointcommission.org

If you have questions about how to file a complaint, you may call The Joint Commission toll-free, 8:30 a.m.–5 p.m. weekdays at 800-994-6610.

You can also contact one of the following agencies with any concerns you have about the hospital or the care your child is receiving:

The Tennessee Department of Health
Health Care Facilities
781-B Airways Blvd.
Jackson, TN 38301-3203
731-421-5106

Quality Improvement Organization (QIO)
Centers for Medicare and Medicaid Services (CMS)
3175 Lenox Park Blvd., Suite 309
Memphis, TN 38115
800-528-2655

Notes

9.0 A Promise Kept

9.1 The St. Jude Story

St. Jude Children’s Research Hospital owes its founding to a promise made years ago by a then little-known, struggling entertainer—Danny Thomas.

Shortly before World War II, Thomas had reached a turning point in his life. He was broke, unsuccessful, and his wife was expecting their first child. He knelt in a Detroit church before a statue of St. Jude Thaddeus, the patron saint of hopeless causes. Thomas asked the saint, “Show me my way in life.”

His prayer was answered, and soon he moved his family to Chicago to pursue career offers. A few years later, at another turning point in his life, Thomas again prayed to St. Jude and pledged someday to build a shrine to the saint.

In the coming years, Thomas’ career prospered through films and television, and he became a nationally known entertainer. He remembered his pledge to build a shrine to St. Jude.

In the early 1950s, Thomas began discussing with friends what concrete form his vow might take. Gradually, the idea of a children’s hospital, possibly in Memphis, took shape. In 1955, Thomas and a group of Memphis businessmen decided to create a unique research hospital devoted to curing catastrophic diseases in children.

Thomas had started raising money for his vision of St. Jude in the early 1950s. By 1955, the local business leaders who had joined his cause began area fundraising efforts. Thomas held benefit shows that brought scores of major entertainment stars to Memphis. Often accompanied by his wife, Rose Marie, Thomas crisscrossed the United States by car. On these trips, he talked about his dream and raised funds at meetings and benefits. The pace was so hectic that Thomas and his wife once visited 28 cities in 32 days. Although Thomas and his friends raised the money to build the hospital, they now faced the daunting task of funding its annual operation.

To solve this problem, Thomas turned to his fellow Americans of Arabic-speaking heritage. He believed that as a group Arabic-speaking Americans should thank the United States for the gifts of freedom given their parents. Thomas also felt the support of St. Jude would be a noble way of honoring his immigrant forefathers who had come to America.

Responding to his plea, 100 representatives of the Arab-American community met in Chicago in 1957 to form ALSAC® with a sole purpose of raising funds to support St. Jude Children’s Research Hospital®.

Since that time, this group, with national headquarters in Memphis and regional offices throughout the United States, has assumed full responsibility for all the hospital’s fundraising efforts. ALSAC raises millions of dollars each year from people of all ethnic, religious, and racial backgrounds. Today, ALSAC is one of America’s largest health care charities, and it is supported by the efforts of more than a million volunteers nationwide.

Thomas fulfilled his pledge to St. Jude Thaddeus when St. Jude Children’s Research Hospital opened its doors February 4, 1962. It is now recognized as one of the world’s premier centers for the study and treatment of catastrophic diseases in children. Many diseases that were seen as incurable in the past are now yielding to treatments developed at St. Jude.

Before his death in 1991, Danny Thomas had seen his little hospital grow to become a beacon of hope for ill children around the world. Although Thomas is no longer with us, his dream of curing all childhood illnesses lives on at St. Jude Children’s Research Hospital.

9.2 Danny Thomas/ALSAC Pavilion

The gold-domed Danny Thomas/ALSAC Pavilion is a tribute to the work of:

- ◆ St. Jude Children’s Research Hospital;
- ◆ ALSAC;
- ◆ Danny Thomas, who founded both organizations; and
- ◆ The Board of Directors and Governors who oversee Danny’s dream.

The pavilion opened in September 1985. It is designed with four wings that provide a self-guided tour of the hospital’s clinical and scientific accomplishments, ALSAC’s fundraising success, and highlights of Danny Thomas’ life and career. Among cases filled with family pictures, movie posters, magazine covers and dozens of candid photos, there are many awards, trophies and honorary degrees that Thomas earned in his work for ALSAC/St. Jude. Throughout the pavilion, push-button videos add to the history of Thomas, the organizations he founded, and the founding members of the Boards of Directors and Governors. The pavilion also offers a chapel for quiet meditation.

9.3 Danny Thomas Memorial Garden

Danny Thomas and Rose Marie Thomas were laid to rest in a family crypt at the west side of the pavilion. The garden fronting the crypt provides a quiet setting for visitors, patients, families, and employees.

As time allows, we hope you will tour the pavilion and visit the garden to learn more about the man who dreamed of a better world for all children.

10.0 What to Bring with You to St. Jude

- ☐ A government-issued photo identification (ID) card for parent(s) (driver's license, passport, or other official ID)
- ☐ Custody or divorce papers, when needed, to verify who can sign for your child's medical tests and treatments
- ☐ A certified copy of your child's birth certificate
- ☐ Social Security numbers of patient and parent(s) or guardian(s)
- ☐ For patients 18 and older, copies of their advance directives—such as living wills or durable powers of attorney for health care
- ☐ Employer information for patient, parent(s) or guardian(s)
- ☐ Emergency contact(s) name, address, and phone numbers
- ☐ Insurance information (including medical, pharmacy, and dental insurance cards)
 - ☐ Your doctor's name, address, phone, fax, and email address
 - ☐ The insurance company or that your insurance company assigned as your child's primary care physician (have address, phone, fax, and email address)
- ☐ Clothing for you and your child to last 7–10 days. Remember: Memphis-area weather might be different than it is where you live. Visit the National Weather Service website to check the Memphis weather forecast (www.nws.noaa.gov).
- ☐ Photographs of family, friends, and pets to help your child cope with feeling homesick
- ☐ A small number of comfort items for your child, such as a blanket or toys (Only smooth-surfaced, easy-to-wash toys are allowed in inpatient rooms. If your child needs a small blanket or cloth toy for comfort, discuss this with your St. Jude doctor. If allowed, these items will need regular washing.)
- ☐ Your child's robe and slippers (If your child becomes an inpatient, hospital gowns, toothbrushes and toothpaste will be provided.)
- ☐ Bring extra supplies of prescription medicines for anyone coming with the patient (Be prepared for an extended stay just in case.)
- ☐ Prescription medicines for the patient

If your trip to St. Jude includes air travel, pack all prescription medicines and important papers in a carry-on bag.

Questions to ask

[illegible]



St. Jude Children's Research Hospital

ALSAC • Danny Thomas, Founder

Finding cures. Saving children.

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