



**Be  
Your  
Own  
Advocate**

Guidebook for Patients

A young boy with brown hair and blue eyes is the central focus, holding a large white sign with the word 'SURVIVING' written in blue, bold, sans-serif capital letters. He is wearing a black t-shirt with 'TEAM PRESTON' printed in purple. The background is a blurred outdoor setting with green grass, trees, and other people, including a woman in a red jacket and a man in a white cap. There are also orange and red balloons visible. The overall atmosphere is one of a community event or rally.

SURVIVING

*Preston,*  
*leukemia survivor*

Be  
Your  
Own  
Advocate



## *Our Mission*

*Cure leukemia, lymphoma,  
Hodgkin's disease and  
myeloma, and improve the  
quality of life of patients  
and their families.*

## **Be Your Own Advocate Patient Guidebook**

**The Leukemia & Lymphoma Society (LLS)** is the world's largest voluntary health agency dedicated to blood cancer. LLS funds lifesaving blood cancer research around the world and provides free information and support services.

As part of our support services to individuals newly diagnosed with blood cancer, we have created this personal guidebook to help you navigate the information and details pertaining to your treatment plan. We know it is difficult to keep track of significant data: doctor's appointments, special procedures, test results, insurance documents, receipts for various expenses (co-pays and parking fees) and other items that you accrue with each hospital or physician visit. This guidebook will allow you to be your own advocate.

The Leukemia & Lymphoma Society offers you this guidebook as a personal companion for each treatment-related appointment. Bring it with you to all of your appointments and use it to store any document that belongs to your treatment plan. As a precaution, do not use it to store personal identity documents such as your driver's license, social security, insurance or credit cards. Information that you will find inside includes:

- A monthly calendar to notate all that occurs before, during and after your medical appointments
- A list of frequent questions for you to ask your doctor, with space to take notes
- Easily accessible phone numbers to many local resources
- Additional printed materials with important information related to your treatment
- Pockets in which you can place pertinent treatment information

The Leukemia & Lymphoma Society is here to help you and has many programs to offer to blood cancer patients and their families.

To learn more, visit our local web site:  
[www.lls.org/il](http://www.lls.org/il) or call us at (312) 651-7353 or (800)742-6595.

Your medical team's opinion is valuable. LLS does not offer medical advice or support a specific health care provider or medical facility.

On behalf of the LLS Patient Access Team, we want to express our gratitude for letting us help you during this personal experience.

The Greater Illinois Chapter



LEUKEMIA &  
LYMPHOMA  
SOCIETY®

**fighting blood cancers**

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Chicago, IL 60607  
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[www.lls.org/il](http://www.lls.org/il)

# Be Your Own Advocate

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*Caesar,  
leukemia survivor*

**Be  
Your  
Own  
Advocate**

**I WALK**





1

Your  
Healthcare  
Team &  
Treatment

## Healthcare Team Members: Who are they and what are their roles?

The team of healthcare providers who will administer your treatment is sometimes called a “multidisciplinary” team in that they are professionals from across different specialties and departments within the hospital. This dedicated group of professionals works in concert to provide you the best treatment plan. Because they are instrumental to your care, it can be helpful to know more about their specific roles. If you have any questions, don't hesitate to ask members of your healthcare team about their role or the specific care they are providing. Below is a list of various care providers and their roles:

### Physicians

Primary care, general practitioner or internal medicine physicians provide general healthcare. They are usually the doctors who refer patients to hematologists and oncologists for treatment of blood cancers. Following completion of your treatment, you will continue to see your primary physician for general healthcare needs.

Physicians receive training at a university or teaching hospital. If you are being treated at one of these facilities, you might encounter the following types of doctors: **attending physicians** have medical degrees and have completed residency training; **fellows** are doing further training in a specialty after having completed medical school and residency training; **residents** work with attending physicians to become certified in a particular specialty after having graduated from medical school and completing an internship; **interns** must be supervised by a senior physician while they train in a general area of medicine following medical school graduation; **medical students** have completed two to three years of medical school and work in hospitals under the supervision of attending physicians.

**Anesthesiologists** administer drugs or other treatments for pain management, most often during and after surgery, as well as other procedures.

**Hematologists**, medical oncologists and radiation oncologists are physicians specializing in cancer treatment.

**Physiatrists** are certified in physical medicine and rehabilitation and work with patients dealing with physical impairment and the loss of function.

**Physician's Assistants (PAs)** are licensed to practice specific aspects of medicine under the supervision of a physician.

**Pathologists** study cells and tissues, and interpret lab test results to confirm a patient's diagnosis.

**Surgeons or surgical oncologists** can operate and usually specialize in the surgical removal of cancer.

### **Nurses**

**Registered nurses (RNs)** have completed a specific amount of training and have a nursing degree. RNs provide care under the order of a physician, nurse practitioner or a physician's assistant. Many RNs are certified in caring for patients in a particular specialty, such as oncology.

**Nurse practitioners (NPs)** or advanced practice nurses (APNs) are registered nurses who have completed graduate-level studies in nursing and have advanced training in a specific field, such as oncology. NPs and APNs work closely with physicians, and can prescribe medications, as well as diagnose, treat and manage a patient's care.

**Certified nursing assistants (CNAs)** have completed a specific amount of training and are supervised by nurses or other medical staff. CNAs provide practical care, such as help bathing.

### **Other Healthcare Team Members**

**Case managers** or care managers guide patients from diagnosis through treatment, providing cohesion to other professionals on your healthcare team.

**Chaplains** provide spiritual support to patients and families. Most hospitals employ chaplains from a variety of faith backgrounds and denominations.

**Child Life Specialists** use their knowledge of child development to help prepare and support children and their families through various components of diagnosis and treatment. They promote the involvement of parents or other family members as partners with the child's healthcare team.

**Dietitians or nutritionists** are food and nutrition experts who help guide and counsel patients on nutritional eating.

**Occupational therapists (OTs)** are trained to help people return to or improve upon activities that are important to everyday living, such as dressing, bathing or working.

**Patient navigators** support and guide patients through the many components of care from diagnosis through treatment, which can include setting up appointments, referring patients to support services and helping with paperwork. Patient navigators also maintain communication between the patient and other members of his or her healthcare team.

**Physical therapists (PTs)** provide services to help patients regain function, improve mobility, relieve pain and prevent or limit permanent physical impairment.

**Psychiatrists, psychotherapists and psychologists** assist patients with mental or emotional challenges that arise from being diagnosed with cancer. Psychiatrists are medical doctors who can prescribe medications.

**Social workers** provide psychosocial support to patients and their families. They help plan for patients' needs after discharge from hospitals, and may help arrange for at-home services.

**Specialty Pharmacies** carry more types of prescriptions than chain or neighborhood pharmacies. Some cancer prescriptions can only be filled at these specialty pharmacies. Ask your healthcare team where your prescriptions can be filled.

*Talk to your doctor about any clinical trials for which you might qualify, and find out if your doctor recommends them for you.*

*Participants in clinical trials can play a more active role in their own health care, gain access to new research treatments before they are widely available, and help others by contributing to medical research.*

## Medical Contacts

Primary Care Physician \_\_\_\_\_

Telephone \_\_\_\_\_

Email \_\_\_\_\_

Nurse \_\_\_\_\_

Telephone \_\_\_\_\_

Email \_\_\_\_\_

Primary Oncologist \_\_\_\_\_

Telephone \_\_\_\_\_

Email \_\_\_\_\_

Oncology Nurse \_\_\_\_\_

Telephone \_\_\_\_\_

Email \_\_\_\_\_

Radiation Oncologist \_\_\_\_\_

Telephone \_\_\_\_\_

Email \_\_\_\_\_

Surgeon \_\_\_\_\_

Telephone \_\_\_\_\_

Email \_\_\_\_\_

Psychologist \_\_\_\_\_

Telephone \_\_\_\_\_

Email \_\_\_\_\_

Hospital \_\_\_\_\_

Telephone \_\_\_\_\_

Email \_\_\_\_\_

Medical Lab \_\_\_\_\_

Telephone \_\_\_\_\_

Email \_\_\_\_\_

## Medical Contacts

Primary Care Physician \_\_\_\_\_

Telephone \_\_\_\_\_

Email \_\_\_\_\_

Nurse \_\_\_\_\_

Telephone \_\_\_\_\_

Email \_\_\_\_\_

Primary Oncologist \_\_\_\_\_

Telephone \_\_\_\_\_

Email \_\_\_\_\_

Oncology Nurse \_\_\_\_\_

Telephone \_\_\_\_\_

Email \_\_\_\_\_

Radiation Oncologist \_\_\_\_\_

Telephone \_\_\_\_\_

Email \_\_\_\_\_

Surgeon \_\_\_\_\_

Telephone \_\_\_\_\_

Email \_\_\_\_\_

Psychologist \_\_\_\_\_

Telephone \_\_\_\_\_

Email \_\_\_\_\_

Hospital \_\_\_\_\_

Telephone \_\_\_\_\_

Email \_\_\_\_\_

Medical Lab \_\_\_\_\_

Telephone \_\_\_\_\_

Email \_\_\_\_\_

## **Working with Your Healthcare Team**

Your care and treatment for blood cancer is very much a team effort, and you are the most important member. When you are being treated for cancer, circumstances may seem beyond your control. However, you play an integral part in developing your care plan, along with your physicians and other members of your care team.

Depending on the details of your health insurance, you may have some choice as to which hospital you attend for treatment. It is important for you to feel comfortable with your oncologist and all members of your healthcare team. You should talk freely and in detail about your symptoms, pain and any other changes you notice in your body. Ask any questions that you have regarding all aspects of your treatment. If at any time you feel like your personal style is not a good fit with a member of your team, don't hesitate to share your concerns. Discussing your concerns directly with your healthcare team member is often the best approach, but if you feel uncomfortable, bring your concerns to someone you trust. Many hospitals have patient advocates whose role is to solve problems between patients and healthcare staff.

If you are not feeling well, or if it would make you more comfortable, having someone else with you at appointments might be helpful. Enlist the help of a trusted family member, friend or social worker to accompany you to tests and appointments.

## **Familiarize Yourself with Policies and Procedures**

Equally important to getting to know your healthcare team is learning about all policies and procedures important to the various components of your treatment. Familiarize yourself with what to do in the following situations:

### **Reaching your physician**

You will have needs and concerns that occur outside of regular appointments. Ask your doctor how they prefer to be reached in these situations, such as a phone call, email, answering service or paging system. Find out how your physician handles emergencies when they are not available. Most physician offices recommend patients go to the hospital emergency room or dial 911.



## **Obtaining Test Results**

To reduce the anxiety that waiting can cause, ask how you should obtain test results. Physician offices vary as to whether they contact you with the results or ask that you call into their office. In most instances, your physician will want to discuss the results with you. You should always feel free to ask questions until you understand the results. Be sure to reference the Understanding Lab and Imaging Tests booklet in the back of this guidebook.

## **Confidentiality**

Healthcare providers are required to protect the privacy of patients under the Health Insurance Portability and Accountability Act (HIPAA). You will be asked to read and sign a HIPAA form prior to your treatment and to provide the names of people with whom your healthcare information can be shared. Ask questions before signing the forms and find out who else will have access to your information, such as your insurance provider.

## **Preparing for Appointments**

Preparing in advance for doctor appointments can be beneficial to both you and your healthcare team. This guide will provide a list of questions to ask your physician. Prior to your appointments, write down any additional questions you have to share with your doctor. These can include:

- General concerns about your treatment as well as any emotional concerns, such as depression
- Pain, new symptoms or any new side effects you have noticed
- Any other treatments you have had, including a massage or acupuncture
- Current medications (including prescriptions, over-the-counter drugs, vitamins and nutritional supplements) and dosages

## **Suggested Items to Bring to Appointments**

Your course of treatment will include many appointments for tests, to see your doctor or for treatment. To make efficient use of your time as well as stay comfortable during these visits, we have created the following checklists to help you make the most of your appointments, including suggestions on what to bring and what to leave at home.

## What to Bring to the Hospital Checklist

- Photo ID (driver's license or state identification card) and insurance card
- Pajamas, nightgown and robe, if you wish
- Personal toiletries, such as shampoo, toothbrush, toothpaste, lotion (hospital rooms tend to be dry)
- Comfortable clothes to wear home
- Money (including change) to purchase newspapers, magazines, etc.
- Assistive devices such as walkers, crutches, canes, hearing aids or magnifying glasses labeled clearly with your name
- A list of prescription medications, dosages and schedule. Ask your physician beforehand if you should bring any of your medications to the hospital (a page to list medications is included on page 1.6)
- Names and phone numbers of family members or friends to contact in an emergency
- Written list of past hospitalizations, illnesses, surgeries and allergies
- A copy of your Advance Directives, including the Living Will or Durable Power of Attorney for Health Care, if available

## Discharge Checklist

The following is designed to help you prepare to leave the hospital:

Review with your physician, nurse or pharmacist all information about the medications and care you will need at home

Pick up any prescriptions that you need from the Professional Building pharmacy

Check your room for any belongings you may have left in the drawers or closet

Pick up any valuables you may have left with the Admitting/Registration Department

Confirm that you have transportation home and that you will be picked up at the appropriate entrance

### **Infusion and/or Radiation Day Checklist**

Infusion therapy and radiation therapy does not require much preparation on your part. However, there are a few things to keep in mind for your treatment day. Use this checklist before each appointment to make sure you are ready:

- Talk to your doctor if you have any questions about your treatment regimen.
- Be sure to tell your doctor or nurse about any concerns you have before beginning your infusion or radiation session.
- Pack something to eat or drink. You may be at the clinic most of the day, so you may want to bring snacks or a prepared meal. Ask your doctor or nurse if there are any special rules about what you should eat or drink before an infusion.
- Bring activities such as crossword puzzles or a book to help you pass the time.
- Arrange transportation. The medications to reduce side effects may make you drowsy or dizzy, so it is a good idea to have someone else drive you home after treatments.
- Remind your doctor or nurse of the medications you take. They may give you special instructions for the day.

### **Please do not bring:**

- Valuables such as, jewelry, credit cards and checkbooks. Most hospitals are not responsible for your belongings. If you must bring valuables, ask to have them deposited in the hospital safe.
- Personal electrical appliances such as heating pads, televisions and radios.

## Medications Tracker

Through the course of your treatment you may be prescribed a variety of medications, in addition to any you were taking prior to your diagnosis. The medications you are taking and their doses are critically important to your treatment and it is a good idea to have a list of each type and dosage documented. We have provided these pages to help you keep track.

Date Prescribed	Name of Medication	Dosage

Date Prescribed	Name of Medication	Dosage

*We've listed some questions that are important for you to ask your physician on each visit.*

*As a suggestion, write down your own questions before your appointment to ensure all your concerns are addressed each time. Additional questions can be found in the education resources section at [www.lls.org/whattoask](http://www.lls.org/whattoask).*

## Questions to Ask to Your Doctor

Date of visit \_\_\_\_\_

Dr. \_\_\_\_\_

1. What does my blood analysis show?

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2. When should I repeat blood work?

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3. Can I get a copy of these tests for my records?

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4. What other exams should I need and when?

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5. I've experienced the following symptoms prior to my visit.  
What's the reason?

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6. What can I do to control these symptoms?

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7. How is the progress of my disease?

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8. Am I going to have a change in my treatment schedule,  
dose or medication? Why?

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9. What kind of medication do I need to take at home and how often?

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10. Why do I have to take them?

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11. Is there anything I should avoid?

What kind of precautions do I need to take at home?

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12. What exactly is my diagnosis?

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13. What's the goal of treatment – to cure or to control my symptoms?

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14. Are you the right doctor to treat my specific disease?

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15. How much experience do you have treating patients with my disease?

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16. What options are available for my diagnosis?

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17. Can I get written information about my illness and treatment?

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18. What is the stage, type and spread of my cancer and what does this mean for me?

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19. Can I participate in a clinical trial? If so, what is the trial testing? What are my benefits and risks?

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20. How should I prepare for this financially?

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21. Is this type of cancer caused by genetic factors? Are other members of my family at risk?

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22. Where can I find more information about my type of cancer?

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23. What lifestyle changes – such as diet, exercise, and rest – do you recommend I make to stay as healthy as possible before, during, and after treatment?

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24. What's the best time to call you if I have a question?

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25. What are the chances that the cancer may come back with the treatment plans we've discussed? What would we do if that happens?

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26. How do I reach you after hours or on weekends and holidays if necessary?

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*Asking your healthcare provider questions can help you take an active role in managing your care. If you do not understand any part of the information your healthcare provider gives you, ask him or her to explain it in another way.*

## Questions About Taking Medications at Home

Doctor's Name \_\_\_\_\_

Name of Medication \_\_\_\_\_

Date of appointment or call \_\_\_\_\_

1. What if I miss a dose?

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2. What if I vomit right after I take my medication?

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3. Is it okay to drink alcohol during my treatment?

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4. When should I take my medication?

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5. For how long do I take my medication?

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6. How should I store my medication?

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7. Do I need to take this medication with food?

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8. Are there any potential drug interactions?

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9. What are the possible side effects of this medication?

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10. What should I do if I experience an unexpected side effect to this medication?

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11. What can I do to relieve the side effects?

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12. How does the medication work?

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13. Will this medication cause drowsiness or affect my alertness?

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14. Can I crush my pills?

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15. Is it required to avoid strong sunlight or tanning beds while taking this medication?

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*Asking your healthcare provider questions can help you take an active role in managing your care. If you do not understand any part of the information your healthcare provider gives you, ask him or her to explain it in another way.*

## Questions About Treatment Side Effects

Doctor's Name \_\_\_\_\_

Date of appointment or call \_\_\_\_\_

1. What are common side effects of this treatment?

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2. What are less common side effects of this treatment?

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3. How will the treatment affect my sexual health?

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4. How will my treatment affect my menstrual cycle?

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5. Will treatment side effects change my appearance? If so, will the changes be permanent or temporary?

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6. Will my treatment cause any sleeping problems, such as insomnia?

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7. How long will the side effects most likely last?

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8. When should I contact a member of my health care team about a side effect?

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9. When are side effects likely to happen?

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10. Are there any side effects I should tell my doctor about right away?

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11. What can I do to ease side effects?

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12. How will my treatment affect fertility, pregnancy or breastfeeding?

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13. What are the long-term and late effects of my treatment?

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A close-up portrait of a Black woman with voluminous, curly hair, smiling warmly. She is wearing large hoop earrings and a necklace made of seashells. The background is a soft, light gradient.

*Shelia*

lymphoma survivor

Be  
Your  
Own  
Advocate



# 2

## Your Support System

## How Your Support System Can Help

Following a diagnosis of cancer, you may find support from family, friends and loved ones who rally around you. Or you may choose to keep your diagnosis and treatment very private. How you choose to deal with your diagnosis and treatment is an extremely individual choice. However, there may be times when extra support is needed. A support system composed of friends, family and/or organizations with experience in helping people through medical challenges can assist with a variety of needs, from practical tasks like housekeeping, meal preparation and navigating insurance issues to the emotional support of an attentive ear to listen to your concerns.

Members of your support system can help you by:

- Assisting with day-to-day needs (meal preparation, housekeeping, laundry, etc.)
- Setting up child care services or transportation
- Researching information and finding services you need
- Finding help for insurance and financial matters
- Keeping track of your healthcare needs and appointments
- Talking with your healthcare team on your behalf, particularly at times when you may not feel physically or emotionally up to the task
- Being a supportive listener if you need help solving a problem or if you feel the need to share concerns about the day-to-day impact of your diagnosis and treatment

## Organizing Your Support System

Although it might be difficult or uncomfortable to ask for help, you will find that most people feel good about helping others, particularly if that person is a family member, friend or neighbor who cares about you. Remember that in a similar situation you would probably want to do the same thing for a family member or loved one.

To foster appropriate personal boundaries and to make sure you're getting help with what you really need, here are some ideas for organizing your support system:

- Create a list of tasks that others can help you complete
- Make a list of people who can provide help and support
- Contact your list of potential support system members; ask when and how they would be willing to help
- Create a schedule with dates, times, tasks and names of people who have agreed to help (see our sample schedule).
- Keep the schedule and share copies with your support system members.

The chart on pages 2.2 - 2.3 can help you to organize the tasks for which you need help, who can assist you and when assistance is needed.

### **Online Resources to Assist with Your Support System**

There are a number of online resources that let you create web pages to keep friends and family updated on your health status, share any needs you might have and allow these important people to send you words of encouragement. Here are a few examples. Also, please see the "Resource Tab" of this guidebook for other useful referrals and resources.

#### **Lotsa Helping Hands**

[www.lhs.lotsahelpinghands.com](http://www.lhs.lotsahelpinghands.com)

Lotsa Helping Hands is a simple, immediate way for friends, family, colleagues and neighbors to assist loved ones in need.

It's an easy-to-use, private group calendar, specifically designed for organizing helpers, where everyone can pitch in with meal delivery, rides and other tasks necessary for life to run smoothly during times of medical crisis, end-of-life caring, or family caregiver exhaustion. It's also a place to keep these 'circles of community' informed with status updates, photo galleries, message boards, and more.

## **Care Pages**

[www.carepages.com](http://www.carepages.com)

CarePages.com is an online community of people who come together to share the challenges, hopes and triumphs of anyone facing a life-changing health event. Through personalized websites, members can relate their stories, post photos and update friends and family instantly. In turn, supporters can send messages of love and encouragement. Care Pages also offers a variety of resources and support tools for living a more compassionate life.

## **CaringBridge**

[www.caringbridge.org](http://www.caringbridge.org)

CaringBridge provides free websites that connect people experiencing a significant health challenge to family and friends, making each health journey easier. CaringBridge websites offer a personal and private space to communicate and show support, saving time and emotional energy when health matters most. The websites are easy to create and use. Authors add health updates and photos to share their story while visitors leave messages of love, hope and compassion in the guestbook.

Help Needed	Days Help is Needed	Times Help is Needed	Helper's Name/Contact Information	Notes/Instructions
Accompany to Medical Appointments				
Cargiving				
Child Care				
Cleaning/ Household Chores				
Help with Insurance Questions				
Help with Bill Payment Questions				

Help Needed	Days Help is Needed	Times Help is Needed	Helper's Name/Contact Information	Notes/Instructions
Laundry				
Meal Preparation				
Pet Care				
Shopping				
Transportation				
Other				





## Important Contact Information for Members of Your Support Team

This information may come in handy if members need to contact each other pertaining to their care assignments.

Name _____
Relationship _____
Telephone _____
Email _____

Name _____
Relationship _____
Telephone _____
Email _____

Name _____
Relationship _____
Telephone _____
Email _____

Name _____
Relationship _____
Telephone _____
Email _____

Name _____
Relationship _____
Telephone _____
Email _____

Name \_\_\_\_\_  
Relationship \_\_\_\_\_  
Telephone \_\_\_\_\_  
Email \_\_\_\_\_

Name \_\_\_\_\_  
Relationship \_\_\_\_\_  
Telephone \_\_\_\_\_  
Email \_\_\_\_\_

Name \_\_\_\_\_  
Relationship \_\_\_\_\_  
Telephone \_\_\_\_\_  
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*Jodi*

*leukemia survivor*

**Be  
Your  
Own  
Advocate**



# 3

## Organizing & Planning Calendars

## Calendars

To help with the organization and planning around your treatments, we are including a monthly calendar. It offers space to write down any kind of event that happened before, during and after your treatment that you would like to share with your physician.

Being organized is quite important, but it can be time consuming, especially if you are not feeling well during your treatment process. You can designate a member of your support team, to do this job instead if it gets to be overwhelming.

To use this calendar, refer to a preprinted calendar or datebook and note the year, month and dates on the blank calendar pages, as shown to the right. Add notes for important appointments, events, tasks or records. Copy and reuse blank calendar pages as needed.

## Appointments and Events

Year 2016

Month

*January*

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
	1	2	3	4	5	6
7	8	9 <i>Oncologist Appt. - 10 am</i>	10	11	12	13 <i>Prescription Pick Up</i>
14	15	16	17	18 <i>Radiation Treatment 3 pm</i>	19	20
21	22	23	24	25	26	27
28	29	30	31			

## Appointments and Events

Month

Year

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday



Record special concerns, events or symptoms that you experienced during this particular period, so you can share this information with your doctor each time you visit the hospital.

**Date:**

**Notes:**




Record special concerns, events or symptoms that you experienced during this particular period, so you can share this information with your doctor each time you visit the hospital.

**Date:**

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Record special concerns, events or symptoms that you experienced during this particular period, so you can share this information with your doctor each time you visit the hospital.

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Record special concerns, events or symptoms that you experienced during this particular period, so you can share this information with your doctor each time you visit the hospital.

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Record special concerns, events or symptoms that you experienced during this particular period, so you can share this information with your doctor each time you visit the hospital.

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Record special concerns, events or symptoms that you experienced during this particular period, so you can share this information with your doctor each time you visit the hospital.

**Date:**

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## Appointments and Events

Month

Year

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

Record special concerns, events or symptoms that you experienced during this particular period, so you can share this information with your doctor each time you visit the hospital.

**Date:**

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Record special concerns, events or symptoms that you experienced during this particular period, so you can share this information with your doctor each time you visit the hospital.

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Record special concerns, events or symptoms that you experienced during this particular period, so you can share this information with your doctor each time you visit the hospital.

**Date:**

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**Appointments and Events**

Month

Year

Sunday

Monday

Tuesday

Wednesday

Thursday

Friday

Saturday


Record special concerns, events or symptoms that you experienced during this particular period, so you can share this information with your doctor each time you visit the hospital.

**Date:**

**Notes:**


## Appointments and Events

Year

Month

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday



Record special concerns, events or symptoms that you experienced during this particular period, so you can share this information with your doctor each time you visit the hospital.

**Date:**

**Notes:**




## **Weekly Schedules**

Use this section to record and/or keep track of things that recur on a weekly basis. Medications you need to take, your medical appointments, your kids' activities, rides or meals needed, etc.

You may choose to photocopy the blank pages or to write in pencil so you can make updates as your regular schedule changes.

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Grace  
*lymphoma survivor*

Be  
Your  
Own  
Advocate



**4**

**Healthcare  
Insurance &  
Benefits**

## Healthcare Insurance & Benefits

Your care and treatment will generate a large amount of paperwork in the form of invoices from healthcare providers and EOB's (Explanation of Benefits) from your insurance company on the various medical services you receive. The nuances of your insurance plan and keeping track of whether these services have been paid - either by you or by your insurer - can be confusing.

To help ease the stress of this challenging, but important, component of your care, we have included definitions of common insurance terms that may be new to you. Italicized words are defined elsewhere on the page.

We have also created a chart to help track the various services for which you are billed. Feel free to use the spreadsheet provided here, or if you would like to keep track on your computer, we recommend setting up an excel spreadsheet similar to the chart on page 4.3. Some insurance providers will allow you to download your EOBs by date range into an excel spreadsheet, which decreases the amount of data entry.

You can find other helpful resources at [www.LLS.org/resourcecenter](http://www.LLS.org/resourcecenter).

## Insurance Definitions

### Coinsurance

A percentage of each claim above the deductible paid by the patient. For example, in a 20% health insurance coinsurance clause, the patient first pays the deductible (which is usually a fixed amount), and then 20% of the bills thereafter - up to a maximum out-of-pocket expense. Coinsurance percentages may differ for different providers (in-network vs. out-of-network) and/or for different types of services.

### Copayment

A predetermined, flat fee a patient pays for healthcare services, in addition to what insurance covers. For example, some plans require a \$20 copayment for each office visit, regardless of the type of level of services provided during the visit. Copayments are not usually specified by percentages. There may be separate copayments for different services. Some plans require that a deductible first be met for some specific services before a copayment applies.



## **Deductible**

A fixed dollar amount during the benefit period (usually a year) that the patient pays before the insurer starts to make payments for covered medical services. Plans may have both per individual and per family deductibles. Some plans may have separate deductibles for specific services. For example, a plan may have a hospitalization deductible per admission. Deductibles may differ if services are received from an approved provider or if received from providers not on the approved list.

## **Explanation of Benefits (EOB)**

A document provided by your insurance plan that explains how much was charged for each service, how much the insurance plan will pay, and how much the patient will be required to pay. When you receive a bill from your physician or hospital, look at the EOB for that service and make sure you are being charged the correct amount.

## **Lifetime Maximum**

The maximum amount payable by the insurer for covered expenses for the insured and each covered dependent while covered under the health plan. The most typical lifetime maximum is \$1 million per individual.

## **Managed Care Provisions**

Features within health plans that provide insurers with a way to manage the cost, use and quality of healthcare services received by patients. Examples of managed care provisions include:

- Preadmission certification: An authorization for hospital admission given by a healthcare provider to a patient prior to their hospitalization. Failure to obtain a preadmission certification in non-emergency situations reduces or eliminates the healthcare provider's obligation to pay for services rendered.
- Utilization review: The process of reviewing the appropriateness and quality of care provided to patients. Utilization review may take place before, during, or after the services are rendered.

- Preadmission testing: A requirement designed to encourage patients to obtain necessary diagnostic services on an outpatient basis prior to non-emergency hospital admission. The testing is designed to reduce the length of a hospital stay.
- Non-emergency weekend admission restriction: A requirement that imposes limits on reimbursement to patients for non-emergency weekend hospital admissions.
- Second surgical opinion: A cost-management strategy that encourages or requires patients to obtain the opinion of another doctor after a physician has recommended that a non-emergency or elective surgery be performed. Programs may be voluntary or mandatory in that reimbursement is reduced or denied if the participant does not obtain the second opinion. Plans usually require that such opinions be obtained from board-certified specialists with no personal or financial interest in the outcome.

### **Maximum Out-of-Pocket Expense**

The maximum dollar amount a patient is required to pay out-of-pocket during a year. Until this maximum is met, the plan and patient share in the cost of covered expenses, often up to a lifetime maximum.

### **Premium**

The dollar amount you pay every month to your health insurance company, even when you do not go see your doctor.

## The Affordable Care Act

In 2014, the Patient Protection and Affordable Care Act, commonly known as Obamacare, came into effect. The goal of the law is to give patients the stability and flexibility they need to make informed choices about their health. Below we have listed some key features of the Affordable Care Act, as provided by HHS.gov.

- Ends pre-existing condition exclusions for children: Health plans can no longer limit or deny benefits to children under 19 due to a pre-existing condition
- Keeps young adults covered: If you are under 26, you may be eligible to be covered under your parent's health plan
- Ends arbitrary withdrawals of insurance coverage: Insurers can no longer cancel your coverage just because you made an honest mistake
- Guarantees your right to appeal: You now have the right to ask that your plan reconsider its denial of payment
- Ends lifetime limits on coverage: Lifetime limits on most benefits are banned for all new health insurance plans
- Reviews premium increases: Insurance companies must now publicly justify rate hikes
- Helps you get the most from your premium dollars: Your premium dollars must be spent primarily on health care - not administrative costs
- Protects your choice of doctors: Choose the primary care doctor you want from your plan's network
- Removes insurance company barriers to emergency services: You can seek emergency care at a hospital outside of your health plan's network

## **Health Insurance Marketplace**

Everyone is required to have health insurance under the new healthcare law, the Affordable Care Act (Obamacare). However, you can't just go out and buy it any time you want. There's a limited open enrollment period during which you can sign up for a new plan or change your current plan.

The only exception to that is if you experience certain life-changing events, such as divorce, pregnancy, the loss of employer-provided coverage, or a qualified hardship.

If you do not have health insurance, then you can purchase insurance on the Health Insurance Marketplace. You can also purchase insurance on the marketplace if the company that you work for gives you insurance and you are not happy with it.

For information on enrollment, go to [www.healthcare.gov](http://www.healthcare.gov).

## **Health insurance plans and network types: HMO, PPO, EPO, and POS**

Depending on what is offered in your area, you may find coverage in all plan types. You will want to comparison shop for your health insurance coverage, which is divided into four tiers:

- Platinum plans will cover 90% of a person's health care costs
- Gold plans will cover 80% of a person's health care costs
- Silver plans will cover 70% of a person's health care costs
- Bronze plans will cover 60% of a person's health care cost
- Catastrophic plans will be available to only individuals under the age of 30 or those who are exempt from purchasing coverage. The out of pocket limits of \$6,350 individual and \$12,700 family will apply. No cost sharing is required.

Some examples of plan types you'll find in the Marketplace:

- **Exclusive Provider Organization (EPO):** A managed care plan where services are covered only if you use doctors, specialists, or hospitals in the plan's network, except in an emergency.
- **Health Maintenance Organization (HMO):** A type of health insurance plan that usually limits coverage to care from doctors who work for or contract with the HMO. It generally won't cover out-of-network care except in an emergency. An HMO may require you to live or work in its service area to be eligible for coverage. HMOs often provide integrated care and focus on prevention and wellness.
- **Point of Service (POS):** A type of plan where you pay less if you use doctors, hospitals, and other health care providers that belong to the plan's network. POS plans require you to get a referral from your primary care doctor in order to see a specialist.
- **Preferred Provider Organization (PPO):** A type of health plan where you pay less if you use providers in the plan's network. You can use doctors, hospitals, and providers outside of the network without a referral for an additional cost.

### **Consider Out-of-Pocket costs**

In general, the more you are willing or able to pay out-of-pocket each time you need health care services, the lower your monthly premium payment will be. Usually bronze plans have lower premiums and higher out-of-pocket costs, and platinum plans have higher premiums and lower out-of-pocket costs.

Patients should be sure to look at all the out-of-pocket costs associated with the plans at the lower metal tiers. They will likely include high deductibles, sometimes as much as \$5,000 or \$6,000 at the bronze level. Carriers differ regarding whether or not medications are subject to the deductibles, which is another key feature to ask about.

If you rely heavily on products that are a part of the pharmacy benefit, also look for whether these plans have co-insurance, which requires you to pay a

percentage of the cost of the drug or service and can add up to hundreds or thousands of dollars per month. As a cancer patient, or any patient with high cost medical needs, this quickly becomes unaffordable.

### **What if I can't afford these costs?**

When you buy your insurance from the Marketplace, you may be eligible for financial help to lower the cost of coverage. Financial help is available in the form of tax credits to help pay for monthly premium costs. You may also be eligible for financial help to lower the amount you pay for out-of-pocket costs, making your health insurance more affordable.

### **LLS wants your feedback**

The Leukemia & Lymphoma Society is committed to removing access barriers for blood cancer patients. If you purchase a marketplace plan and later experience high treatment costs, a lack of access to your provider or hospital, or a delay in getting timely care, please share your story with us at [missioncommunications@lls.org](mailto:missioncommunications@lls.org). If you have a positive experience, we would like to hear that too. Making your voice heard can really make a difference.

If you have questions or want more information, please contact LLS's Information Resource Center (IRC) at 1-800-955-4572, Monday to Friday, 9 a.m. to 9 p.m. ET.

### **Helpful links**

<http://obamacarefacts.com/>

<http://obamacare.com/>

<http://obamacare-guide.org/>

## **Reference Sources**

### **Survey definitions from:**

- The National Compensation Survey definitions (BLS)
- The Medical Expenditure Panel Survey definitions (AHRQ)
- The National Employer Health Insurance Survey (NCHS)

### **Definitions from other Federal agencies and surveys such as:**

- The Current Population Survey (BLS/Census)
- Erisa-related definitions (from PWBA)

### **Glossaries and informational papers from websites such as:**

- OPM's Federal Employees Health Benefits Plan (glossary and specific plan booklets)
- Blue Cross/Blue Shield
- The National Center for Policy Analysis
- The Health Insurance Association of America

### **Publications such as:**

- Employee Benefit Plans: A Glossary of Terms, Ninth Edition 1997, Judith A. Sankey, editor, International Foundation of Employee Benefit Plans
- Fundamentals of Employee Benefit Programs, Fourth edition
- Managed Care Plans and Managed Care Features: Data from the EBS to the NCS

# Benefits Tracker

Date of Medical Service	Medical Provider/Service Rendered	Total Amount Billed for Service	Amount of Co-Pay/Date Paid	Amount Paid by Primary Insurer or Benefit Program	Amount Paid by Secondary Insurer or Benefit Program	Balance Due	Paid



# Benefits Tracker

Date of Medical Service	Medical Provider/Service Rendered	Total Amount Billed for Service	Amount of Co-Pay/Date Paid	Amount Paid by Primary Insurer or Benefit Program	Amount Paid by Secondary Insurer or Benefit Program	Balance Due	Paid

# Benefits Tracker

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## Benefits Tracker

Date of Medical Service	Medical Provider/Service Rendered	Total Amount Billed for Service	Amount of Co-Pay/Date Paid	Amount Paid by Primary Insurer or Benefit Program	Amount Paid by Secondary Insurer or Benefit Program	Balance Due	Paid

*Mark*

*Mark, lymphoma survivor*

**SURVIVOR**

Be  
Your  
Own  
Advocate

# Martez

*leukemia survivor*

5

Resources

SURVIVOR

*The Leukemia & Lymphoma Society's  
Patient Access Support & Programs*

*The Leukemia & Lymphoma Society's  
Greater Illinois Chapter offers a  
wide range of free educational and  
support programs for patients, their  
families, caregivers and healthcare  
professionals.*

*Except where indicated, for more  
information contact the Greater Illinois  
Chapter at (312) 651-7353 or toll free  
(800) 742-6595, email  
Patient\_Services\_ILC@lls.org  
or visit our web site at [www.lls.org/il](http://www.lls.org/il).*

### **Information Resource Center (800) 955-4572**

The Information Resource Center is staffed by Information Specialists, master's level oncology professionals. They provide accurate up-to-date disease and treatment information and are available to speak with callers Monday through Friday, 9 a.m. to 9 p.m. ET at (800) 955-4572. You can email [infocenter@LLS.org](mailto:infocenter@LLS.org) or chat live with a Specialist at [www.LLS.org](http://www.LLS.org).

### **Susan Lang Pay-it-Forward**

The Leukemia & Lymphoma Society's (LLS) Susan Lang Pay-It-Forward Patient Travel Assistance program is available to blood cancer patients, with significant financial need, who may qualify to receive financial assistance for approved expenses including: ground transportation (gas, tolls, car rental, taxi, bus, train, ambulance services, etc.), air travel, and lodging related expenses. For eligibility and details please call 844-565-2269 or email [patientassistance@lls.help](mailto:patientassistance@lls.help).

### **Co-Pay Assistance Program**

This program offers assistance for financially eligible patients with certain blood cancer diagnoses to help pay for private or public health insurance premiums and/or co-pay costs for prescription medications.

Visit [www.LLS.org/copay](http://www.LLS.org/copay) or call (877) 557-2672 to speak to a Co-Pay Assistance Program specialist for more eligibility information.

### **Patti Robinson Kaufmann First Connection Program**

This program offers peer to peer support from a well-trained volunteer who has been through a similar situation. The volunteer's own personal experience enables them to relate in a unique and positive way to others who are newly diagnosed. Contact us at (312) 651-7353 for more information.

### **Trish Green Back to School Program**

This back to school program helps children with cancer return to school by providing information to parents, patients, teachers, and classmates. Specially developed material will assist in the transition back to the classroom. Program videos and materials are available for students from preschool to high school. For more information, call us at (312) 651-7353.

## **Family Support Groups**

Our monthly Family Support Groups are designed to offer emotional support and education throughout your cancer journey. Under professional guidance, patients and family members can discuss their anxieties and concerns with others who share a similar experience. This sharing opportunity facilitates improved communication and enhances everyone's ability to cope with their cancer diagnosis. To find a family support group in your area, go to [www.lls.org/il](http://www.lls.org/il) and select "Patient Support Programs".

## **LLS Community**

Join a community of people who understand what you're going through. LLS Community is a place for you to connect with others affected by blood cancers and share your voice to drive change. The resources on LLS community are accurate, up-to-date, and from a trusted source. LLS Community relies on your experiences and insights to drive program development and research studies that address the needs and real-world challenges of patients living with blood cancer. To learn more or join, please visit [communityview.lls.org](http://communityview.lls.org).

## **Online Chats**

Our live, weekly online chats provide a friendly forum to share experiences and chat with others about anything from the initial phase of diagnosis to treatment and survivorship. Each chat is moderated by an oncology social worker. The role of the moderator is to provide support and guide conversation, as needed, throughout the chats. Please visit: [www.lls.org/support/online-chats](http://www.lls.org/support/online-chats)

## **Educational Programs**

The Leukemia & Lymphoma Society (LLS) sponsors many free live and archived teleconferences, podcasts, webcasts and more that you can view at your convenience. In addition, LLS sponsors a number of free community-based professional education programs for healthcare professionals, particularly for oncology nurses and social workers. Patients, their families and caregivers are also invited to attend. For a complete list of our programs see our National Patient Education Programs web page, [www.lls.org/webcasts](http://www.lls.org/webcasts).



### **First Connection Program**

This program offers peer to peer support from a well- trained volunteer who has been through a similar situation. The volunteer's own personal experience enables him/her to relate in a unique and positive way to others who are newly diagnosed.

### **Trish Green Back to School Program**

This back to school program helps children with cancer return to school by providing information to parents, patients, teachers, and classmates. Specially developed material will assist in the transition back to the classroom.

### **Advocacy Network**

The chapter has an active network of volunteers who work with legislators to obtain access to quality medical treatment and legal protection in the health insurance and employment arenas. Involvement in shaping public healthcare policies is possible through the Advocacy Network. Register at <http://action.lls.org>.

### **Family Support Groups**

Open communication is critical for coping with the feelings that arise during illness. Family Support Groups feature sessions led by local healthcare professionals where you can share your concerns, fears, problems and experiences in a comfortable and caring setting.

To find a family support group in your area, go to [www.lls.org/il](http://www.lls.org/il) and select "Patient Support Programs".

### **Online Chats**

Our weekly two-hour online chats provide a friendly forum to share experiences and offer support for people living with non-Hodgkin lymphoma, chronic myeloid leukemia, myeloma and for young adults (aged 18-39) living with blood cancer. Each chat is moderated by an oncology social worker.

[www.lls.org/#/diseaseinformation/getinformationsupport/onlinechats](http://www.lls.org/#/diseaseinformation/getinformationsupport/onlinechats)

### **Honored Hero Program**

Our honored heroes provide inspiration and support for the LLS fundraising programs and are symbols of strength for others dealing with challenges in their lives. An honored hero is anyone who is being treated for, or is a survivor of, leukemia, lymphoma or myeloma. You can participate on several levels, including sharing your story, creating artwork, writing letters or attending fundraising events.

### **Educational Programs**

We offer free educational materials, including disease specific information as well as information on coping, nutrition and side effects of treatments. We also offer educational programs for patients, families and healthcare professionals throughout the year.

### **Alexis' Angels Holiday Program**

Alexis' Angels is a holiday gift-giving program named in honor of Alexis White, who was diagnosed with leukemia at the age of 15. Inspired by the loving memory of their daughter Jim and Patty White deliver holiday gifts to the children of families touched by blood cancer with the help of their Alexis' Angels volunteers. Contact your local chapter to inquire how you can participate in this program.

Throughout your diagnoses and treatment, you will have many options of care. Your healthcare team can help with any question you have and can provide referrals for information and resources. One of the goals of helping you “be your own advocate” is to provide you with a list of reputable organizations dedicated to servicing the needs of cancer patients and their families.

The Leukemia & Lymphoma Society (LLS) is pleased to provide you with the following list of resources that, in our opinion, represent some of the best local and national resources. Please call the Greater Illinois Chapter at (312)568- 7353 for additional information about these resources.

**Resources include:**

- LLS Sponsored Support Groups
- LLS Partnered Support Groups
- Bereavement Support Groups
- Blood Cancer Organizations
- Pediatric Resources
- Teen and Young Adult Resources
- Camp esources
- Peer-to-Peer Support Services Financial Assistance Programs
- Other Useful Resources

## Resources | Support Groups

These support groups are for adults suffering from blood cancers as well as for their families and friends or caregivers. Participants are encouraged to call the facilitator of each group prior to attending.

### LLS Sponsored Support Groups

#### **Blood Cancer Support Group Wellness Place**

1619 W. Colonial Parkway  
Palatine, IL  
(847) 221-2400  
First Tuesday of the month  
[www.wellness.com](http://www.wellness.com)

#### **Blood Cancer Networking Support Group Gilda's Club Chicago**

537 N. Wells Street  
Chicago, IL 60634  
(312) 464-9900  
First Wednesday of the month  
[www.gildasclubchicago.org](http://www.gildasclubchicago.org)

#### **Leukemia & Lymphoma Networking Group Wellness House**

131 N. County Line Road  
Hinsdale, IL 60521  
(630) 654-5114  
Second Thursday of the month  
[www.wellnesshouse.org](http://www.wellnesshouse.org)

#### **Young Adults with Cancer Wellness House**

131 N. County Line Road  
Hinsdale, IL 60521  
(630)323-5150  
Fourth Thursday of the month  
[www.wellnesshouse.org](http://www.wellnesshouse.org)

#### **Leukemia & Lymphoma Networking Group**

Northwest Community Hospital  
800 W. Central Road  
Arlington Heights, IL 60005  
(847) 618-1000  
Second Wednesday of the month  
[www.nch.org](http://www.nch.org)

#### **MDS Networking Group Northwest Community Hospital**

800 W. Central Road  
Arlington Heights, IL 60005  
(847) 618-1000  
Fourth Tuesday of the month  
[www.nch.org](http://www.nch.org)

#### **"Café Con Leche"**

Support groups for Latino cancer patients, survivors and caregivers.

#### **Saint Anthony Hospital**

2875 W. 19th Street, 8th floor  
Chicago, IL 60623  
(773) 484-1000  
Third Tuesday of the month  
[www.saintanthonyhospital.org](http://www.saintanthonyhospital.org)

#### **Gilda's Club Chicago**

537 N. Wells Street  
Chicago, IL 60634  
(312) 464-9900  
Second Wednesday of the month  
[www.gildasclubchicago.org](http://www.gildasclubchicago.org)

## **LLS Partnered Support Groups**

### **Chicago**

#### **Blood Cancer Forum Gilda's Club Chicago**

537 North Wells Street  
Chicago, IL 60654  
(312) 464-9900  
First Wednesday of the month  
[www.gildasclubchicago.org](http://www.gildasclubchicago.org)

#### **Myeloma Support Group Northwestern Memorial Hospital**

676 N. St. Clair St., Feinberg Rm. D  
Chicago, IL 60611  
(312) 695-4523  
First Monday of the month  
[cancer.northwestern.edu](http://cancer.northwestern.edu)

### **Southern Suburbs**

#### **Blood Cancer Forum: Myeloma & Leukemia Cancer Support Center**

2028 Elm Road  
Homewood, IL 60430  
(708) 798-9171  
Third Wednesday of the month  
[www.cancersupportcenter.org](http://www.cancersupportcenter.org)

### **Northern Suburbs**

#### **Leukemia & Lymphoma Cancer Wellness Center**

215 Revere Drive  
Northbrook, IL 60062  
(847) 509-9595  
First Wednesday of the month

Registration Required.  
Call for more info.  
[www.cancerwellness.org](http://www.cancerwellness.org)

#### **Multiple Myeloma Cancer Wellness Center**

215 Revere Drive  
Northbrook, IL 60062  
(847) 509-9595  
First Wednesday of the month  
Registration Required.  
Call for more info.  
[www.cancerwellness.org](http://www.cancerwellness.org)

#### **Cancer Survivor Support Group Cancer Wellness Center**

215 Revere Drive  
Northbrook, IL 60062  
(847) 509-9595  
[www.cancerwellness.org](http://www.cancerwellness.org)

#### **Young Women With Cancer Wellness Place**

1619 W. Colonial Parkway  
Palatine, IL 60067  
(847) 509-9595  
Registration Required.  
Call for more info.  
[www.wellness.com](http://www.wellness.com)

#### **Cancer and Caregiver Support Group Healing Pathways**

Westminster Presbyterian Church,  
Lower Level  
2821 N. Bell School Road  
Rockford, IL 61107  
(815) 282-1500  
[www.healingpathwayscsc.org](http://www.healingpathwayscsc.org)

## Western Suburbs

### **Leukemia, Lymphoma, & Myeloma Networking Group**

Living Well Cancer Resource Center  
442 Williamsburg Ave  
Geneva, IL 60134  
(630) 262-1111  
Third Monday of the month  
Registration Required.  
Call for more info.  
[www.livingwellcrc.org](http://www.livingwellcrc.org)

### **Bone Marrow Transplant Support Group**

Loyola University Medical Center  
2160 S. First Avenue  
Maywood, IL 60153  
(708) 216-4776  
Registration Required.  
Call for more info.  
[www.loyolamedicine.org](http://www.loyolamedicine.org)

### **Cancer and Caregiver Support Group Edward Cancer Center**

120 Spalding Drive  
Naperville, IL 60540  
Third Wednesday of the month  
Call for more info.  
(630) 646-6111

## Central Illinois

### **Adult, Teen, and Children Cancer Support Groups**

Community Cancer Center  
407 East Vernon Ave  
Normal, IL 61761  
(309) 451-8500  
[www.cancercenter.org](http://www.cancercenter.org)

### **General Cancer and Child Support Groups**

Cancer Center for Healthy Living  
5215 Knoxville Avenue  
Peoria, IL 61614  
(309) 693-8139  
Registration Required.  
Call for more info.  
[www.cchlpeoria.org](http://www.cchlpeoria.org)

### **Women's Cancer Support Group**

Simmons Cancer Institute at SIU  
315 W. Carpenter Street  
Springfield, IL 62702  
(217) 545-6000  
[www.siumed.edu/cancer/index.html](http://www.siumed.edu/cancer/index.html)

### **Quality of Life after Cancer Support Group**

St. John's Hospital  
800 East Carpenter Street  
Springfield, IL 62769  
For information call Diana Weyhenmeyer  
(217) 544-6464 ext. 45591

## **Blood Cancer Support Groups**

### **Cancer Wellness Center**

215 Revere Drive  
Northbrook, IL 60062  
(847) 509-9595  
Registration Required.  
Call for more info.  
[www.cancerwellness.org](http://www.cancerwellness.org)

### **Cancer Hope Network**

(630) 232-2233  
Registration Required.  
Call for more info.  
[www.fvvh.org](http://www.fvvh.org)

### **Cancer Center for Healthy Living**

5215 Knoxville Avenue  
Peoria, IL 61614  
(309) 693-8139  
Registration Required.  
Call for more info.  
[www.cchlpeoria.org](http://www.cchlpeoria.org)

### **Living Well Cancer Resource Center**

442 Williamsburg Ave  
Geneva, IL 60134  
(630) 262-1111  
Registration Required.  
Call for more info.  
[www.livingwellcrc.org](http://www.livingwellcrc.org)

### **Chemo Angels**

Online [www.chemoangels.net](http://www.chemoangels.net)

### **Herbie's Friends**

Fox Valley Volunteer Hospice  
200 Whitfield Drive  
Geneva, IL 60134  
(630) 232-2233  
Registration Required.  
Call for more info. [www.fvvh.org](http://www.fvvh.org)

### **KidsKonnected Support Group**

Cancer Center for Healthy Living  
5215 Knoxville Avenue  
Peoria, IL 61614  
(309) 693-8139  
Registration Required.  
Call for more info.  
[www.cchlpeoria.org](http://www.cchlpeoria.org)  
Peer-to-Peer Support

### **Wellspring Clinical Associates**

131 N. County Line Road  
Hinsdale, IL 60521  
(630) 323-5150  
[www.wellnesshouse.org](http://www.wellnesshouse.org)

### **Young Women With Cancer Wellness Place**

1619 W. Colonial Parkway  
Palatine, IL 60067  
(847) 221-2200  
Registration Required.  
Call for more info.  
[www.wellnessplace.org](http://www.wellnessplace.org)

## **Myeloma Support Group**

### **Northwestern Memorial Hospital**

676 N. St. Clair Street, Feinberg  
Conf. Rm. D  
Chicago, IL 60611

### **International Myeloma Foundation**

Online. (800) 452-2873  
[www.myeloma.org](http://www.myeloma.org)

### **Cancer Resource Centre**

926 Ridge Road  
Munster, IN 46321  
(219) 836-3349  
[www.cancerresourcecentre.com](http://www.cancerresourcecentre.com)

### **American Cancer Society**

225 N Michigan Avenue, Suite 121  
Chicago, IL 60601  
(800) 227-2345  
[www.cancer.org](http://www.cancer.org)

### **Cancer Center for Healthy Living**

5215 Knoxville Avenue  
Peoria, IL 61614  
(309) 693-8139  
Registration Required.  
Call for more info.  
[www.cchlpeoria.org](http://www.cchlpeoria.org)

### **Living Well Cancer Resource Center**

442 Williamsburg Ave  
Geneva, IL 60134  
(630) 262-1111  
[www.livingwellcrc.org](http://www.livingwellcrc.org)

## **Bereavement Support Groups**

### **Pathways: Bereavement Support for widowers, parents, children Fox Valley Volunteer Hospice**

200 Whitfield Drive  
Geneva, IL 60134  
(630)232-2233  
Registration Required.  
Call for more info.

### **Horizon Palliative & Hospice Care Center**

833 West Chicago Avenue  
Chicago, IL 60642  
(312) 733-8900  
Registration Required.  
Call for more info.  
[www.journeycare.org/grief-support/](http://www.journeycare.org/grief-support/)

### **Horizon Palliative & Hospice Care Center**

3420 Vollmer Road  
Olympia Fields, IL 60461  
(708) 748-6761  
Registration Required.  
Call for more info.  
[www.journeycare.org/grief-support/](http://www.journeycare.org/grief-support/)

### **Midwest Palliative & Hospice Care Center**

2050 Claire Court  
Glenview, IL 60025  
(847) 467-7423  
Call for more info.  
[www.journeycare.org/grief-support/](http://www.journeycare.org/grief-support/)



## **Blood Cancer Organizations**

In addition to the blood cancer services offered by The Leukemia & Lymphoma Society, organizations exist that focus on your specific disease. We encourage you to contact these diagnoses specific organizations. They may be able to provide additional support services such as educational materials, diagnoses specific resources and financial assistance programs.

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

954 W. Washington Blvd.  
3rd Floor  
Chicago, IL 60607  
312.651.7350  
[www.LLS.org/il](http://www.LLS.org/il)

### **BMT Information Network**

2310 Skokie Valley Road, Suite 104  
Highland Park, IL 60035  
(847) 433-3313  
[www.bmtinfonet.org](http://www.bmtinfonet.org)

### **Delete Blood Cancer**

Online/National  
Ney York, NY  
[www.deletebloodcancer.org/en](http://www.deletebloodcancer.org/en)

### **Lymphoma Research Foundation**

134 N. LaSalle Street Suite 1950  
Chicago, IL 60602  
(312) 263-1717  
[www.lymphoma.org](http://www.lymphoma.org)

### **The Leukemia Research Foundation**

3520 Lake Avenue, Suite 202  
Wilmette, IL 60091  
(847) 424-0600  
[www.leukemia-research.org](http://www.leukemia-research.org)

### **Multiple Myeloma Research Foundation**

383 Main Avenue, 5th Floor  
Norwalk, CT 06851  
(203) 229-0464  
[www.themmr.org](http://www.themmr.org)

### **The Myelodysplastic Syndromes Foundation**

4573 S. Broad Street, Suite 150  
Yardville, NJ 08620  
(800) MDS-0839  
[www.mds-foundation.org](http://www.mds-foundation.org)

### **Resources | Pediatric & Young Adult Resources**

#### **American Childhood Cancer Organization**

PO Box 498  
Kensington, MD 20895  
(855) 858-2226  
[www.acco.org](http://www.acco.org)

#### **Children's Cancer Recovery Foundation**

PO Box 238  
Hershey, PA 17033  
(800) 238-6479  
[www.childrenscancerrecovery.org](http://www.childrenscancerrecovery.org)

**The Children's Leukemia  
Research Association**

585 Stewart Avenue, Suite 18  
Garden City, NY 11530  
(516) 222-1944  
[www.childrensleukemia.org](http://www.childrensleukemia.org)

**Chemo Angels**

Online [www.chemoangels.net](http://www.chemoangels.net)

**Children's Oncology  
Services, Inc.**

213 W. Institute Place, Suite 511  
Chicago, IL 60610  
(312) 924-4220  
[www.onestepcamp.org](http://www.onestepcamp.org)

**A Special Wish Foundation**

PO Box 577248  
Chicago, IL 60657  
(312) 962-4442  
[www.aswchicago.org](http://www.aswchicago.org)

**Bear Necessities Pediatric  
Cancer Foundation**

55 W. Wacker Drive, Suite 1100  
Chicago, IL 60601  
(312) 214-1200  
[www.bearnecessities.org](http://www.bearnecessities.org)

**First Descents**

100 Arapahoe Avenue, Suite 8  
Boulder, CO 80302  
(303) 945-2490  
[www.firstdescents.org](http://www.firstdescents.org)

**Foundation for Children  
with Cancer**

11327 Gravois Road, Suite 202  
St. Louis, MO 63126

(866) 800-8860  
[www.childrenwithcancer.org](http://www.childrenwithcancer.org)

**Group Loop (Teens)  
Online/National**

1050 17th Street, Suite 500  
Washington, DC 20036  
(888) 793-9355  
<http://grouploop.org/>

**I'm Too Young for This  
Cancer Foundation**

40 Worth Street, Suite 808  
New York, NY 10013  
(877) 735-4673  
[www.i2y.org](http://www.i2y.org)

**Kids Konnected**

(800) 899-2866  
[www.kidskonnected.org](http://www.kidskonnected.org)

**LiveStrong Lance Armstrong  
Foundation**

2201 E. Sixth Street  
Austin, TX 78702  
(877) 236-8820  
[www.livestrong.org](http://www.livestrong.org)

**Make-A-Wish Foundation**

640 N. LaSalle Drive, Suite 280  
Chicago, IL 60654  
(800) 978-9474  
[www.wishes.org](http://www.wishes.org)

**Pediatric Oncology Treasure  
Chest Foundation**

15430 70th Court  
Orland Park, IL 60462  
(708) 687-TOYS (8697)  
[www.treasurechest.org](http://www.treasurechest.org)

**Stupid Cancer  
Online/National**

New York, NY  
<http://stupidcancer.org/>

**Super Sibs**

660 N. First Bank Drive  
Palatine, IL 60067  
(847) 462-4742  
[www.supersibs.org](http://www.supersibs.org)

**The Children's Leukemia  
Research Foundation**

Online/ National  
Garden City, NY  
<http://childrensleukemia.org/>

**Ulman Cancer Fund**

6310 Stevens Forest Road  
Columbia, MD 21045  
(888) 393-3863  
[www.ulmanfund.org](http://www.ulmanfund.org)

**UnitedHealthcare Children's  
Foundation**

PO Box 41, MN012-S286  
Minneapolis, MN 55440-0041  
(800) 328-5979  
[www.uhccf.org](http://www.uhccf.org)

**3 Little Birds 4 Life**

808 Pennsylvania St  
Collinsville, IL 62234  
(618) 977-0519  
[www.3littlebirds4life.org](http://www.3littlebirds4life.org)

**Cancer Really Sucks**

[www.cancerreallysucks.org](http://www.cancerreallysucks.org)

**Critical Mass Young Adult  
Cancer Alliance**

2201 E. Sixth Street  
Austin, TX 78702  
(877) 236-8820  
<http://criticalmass.org>

**FertileHOPE**

2201 E. Sixth Street  
Austin, TX 78702  
855.220.7777  
<http://www.fertilehope.org/>

**First Descents**

100 Arapahoe Avenue, Suite 8  
Boulder, CO 80302  
(303) 945-2490  
[www.firstdescents.org](http://www.firstdescents.org)

**Group Loop**

[www.grouploop.org](http://www.grouploop.org)

**I Had Cancer**

[www.ihadcancer.com](http://www.ihadcancer.com)

**LIVESTRONG**

2201 E. Sixth Street  
Austin, TX 78702 (877) 236-8820  
[www.livestrong.org](http://www.livestrong.org)  
En Español: [www.livestrong.org/?lang=es-es](http://www.livestrong.org/?lang=es-es)

**The SAM Fund**

89 South Street, Suite LL02  
Boston, MA 02111  
(617) 938-3484  
[www.thesamfund.org](http://www.thesamfund.org)

## **SeventyK**

[www.seventyk.org](http://www.seventyk.org)

## **Stupid Cancer**

40 Worth Street, Suite 808  
New York, NY 10013  
(877) 735-4673  
[www.stupidcancer.com](http://www.stupidcancer.com)

## **Teens Living with Cancer**

[www.teenslivingwithcancer.org](http://www.teenslivingwithcancer.org)

## **True North Treks**

(773) 972-2367  
[www.truenorthtreks.org](http://www.truenorthtreks.org)

## **Twist Out Cancer**

[www.twistoutcancer.org](http://www.twistoutcancer.org)

## **Ulman Cancer Fund**

6310 Stevens Forest Road, Ste. 210  
Columbia, MD 21046  
[www.ulmanfund.org](http://www.ulmanfund.org)

## **Who Cares:**

### **Teen Cancer America**

[www.teencanceramerica.org](http://www.teencanceramerica.org)

## **The Leukemia & Lymphoma Society**

651 W. Washington Boulevard,  
Suite 400  
Chicago, IL 60661  
(312) 651-7353  
[www.LLS.org/il](http://www.LLS.org/il)

## **Camp Resources**

### **Camp COCO**

For kids aged 6-16 from central or southern Illinois with cancer and their siblings. For information contact: SIU Foundation The School of Medicine 927 N. Rutledge Street, Po Box 19666 Springfield, IL 62794 (217) 545-2955 [www.siumed.edu/foundation/campcoco.htm](http://www.siumed.edu/foundation/campcoco.htm)

### **Camp Hope**

One-week summer day camp in June and August for children aged 6-12 whose parent or family member has cancer. The Camp is located at the Edward Health & Fitness Center in Woodridge. For information call (630) 646-6054/6111 [www.camphopeillinois.org](http://www.camphopeillinois.org)

### **Camp Kesem**

One-week sleep away camp for kids 6-16 who have or had a parent with cancer. Camps are associated with Augustana College, Northwestern University and University of Illinois. [campkesem.org](http://campkesem.org)

### **Camp Quality - Illinois**

One-week camp for kids aged 5-17 that have cancer. The camp is located in Frankfort, IL. For information contact: PO Box 641 Lansing, IL 60438 (708) 895-8311

### **Children's Oncology Services, INC**

One Step at a Time Summer Camp  
One to two-week overnight camp  
for kids aged 7-19 with cancer.

For more information:  
213 West Institute Place, Suite 511  
Chicago, IL 60610  
(312) 924-4220  
[www.onestepcamp.org](http://www.onestepcamp.org)

### **One Step at a Time Chicago Day Camp**

A few days in early Spring for kids  
aged 5-10 with cancer.  
Other One Step at a Time programs  
Dude Ranch, Family Camp, Sibling  
Camp, Ski Program, Springfield  
and DC Advocacy programs,  
Whitewater Adventure and  
a Winter Camp.

For more information:  
213 West Institute Place, Suite 511  
Chicago, IL 60610  
(312) 924-4220  
[www.onestepcamp.org](http://www.onestepcamp.org)

### **TLC Camp**

One-week day camp for kids 5-13  
who have cancer or kids with a  
sibling that has cancer.  
TLC Camp is located in Lombard, IL.  
(630) 730-4290 or  
(630) 464-3974  
[www.tlccamp.org](http://www.tlccamp.org)

### **Resources | Peer-to-Peer Support Resources**

#### **First Connection Program The Leukemia & Lymphoma Society**

6954 W. Washington Blvd.  
3rd Floor  
Chicago, IL 60607  
312.651.7350  
[www.lls.org/il](http://www.lls.org/il)  
En Español: [www.lls.org/espanol](http://www.lls.org/espanol)

#### **Lymphoma Support Network**

#### **Lymphoma Research Foundation**

1700 W. Irving Park Rd.  
Chicago, IL 60613  
(312) 263-1717  
[www.lymphoma.org](http://www.lymphoma.org)

#### **Peer Support Network Aplastic Anemia & MDS International Foundation**

100 Park Avenue, Suite 108  
Rockville, MD 20850  
(800) 747-2820  
[www.aamds.org](http://www.aamds.org)

#### **One-on-One Cancer Support Imerman Angels**

400 W. Erie Street, Suite 405  
Chicago, IL 60654, (312) 274-5529  
Call for more information  
[www.imermanangels.org](http://www.imermanangels.org)

## **Online Communities and Support**

### **American Cancer Society, IL Division**

225 N Michigan Avenue, Suite 1210  
Chicago, IL 60601  
(312) 372-0471  
[www.cancer.org](http://www.cancer.org)  
En Español: [www.cancer.org/espanol](http://www.cancer.org/espanol)

## **Resources | Financial Assistance Programs**

### **12 Oaks Foundation**

960 Harris Road, Suite 2B  
Grayslake, IL 60030  
(847)231-0992  
[www.12oaksfoundation.org](http://www.12oaksfoundation.org)

### **American Cancer Society**

225 N Michigan Avenue, Suite 1210  
Chicago, IL 60601  
(800) 227-2345  
[www.cancer.org](http://www.cancer.org)

### **Bone Marrow Foundation**

30 East End Avenue, Suite 1F  
New York, NY 10028  
(800) 365-1336  
[www.bonemarrow.org](http://www.bonemarrow.org)

### **Brenda Mehling Cancer Fund**

24152 Lyons Avenue, Suite 157  
Santa Clarita, CA 91321  
(661) 310-7940  
[www.bmcf.net](http://www.bmcf.net)

### **Cancer and Careers**

Online/National  
New York, NY  
[www.cancerandcareers.org/en](http://www.cancerandcareers.org/en)

### **Catholic Charities**

721 N LaSalle Street  
Chicago, IL 60625  
(312) 655-7700  
[www.catholiccharities.net](http://www.catholiccharities.net)

### **CancerCare**

275 Seventh Avenue  
New York, NY 10001  
(800) 813-4673  
[www.cancercares.org](http://www.cancercares.org)

### **Chemo Angels**

Online  
[www.chemoangels.net](http://www.chemoangels.net)

### **Chronic Disease Fund**

6900 N. Dallas Parkway, Suite 200  
Plano, TX 75024  
(877) 968-7233  
[www.gooddaysfromcdf.org](http://www.gooddaysfromcdf.org)

### **Gracious Gifts**

Online  
(312) 636-7554  
<https://www.facebook.com/graciousgiftsnonprofit/info>

### **LiveStrong Lance Armstrong Foundation**

2201 E. Sixth Street  
Austin, TX 78702  
(877) 236-8820  
[www.livestrong.org](http://www.livestrong.org)

**Lymphoma Research Foundation**

134 N. LaSalle Street, Suite 1950  
Chicago, IL 60602  
(312) 263-1717  
[www.lymphoma.org](http://www.lymphoma.org)

**The Children's Leukemia Research Association**

Online/ National  
585 Stewart Avenue Suite 18  
Garden City, NY 11530  
<http://childrensleukemia.org/>

**The Leukemia & Lymphoma Society**

954 W. Washington Blvd.  
3rd Floor  
Chicago, IL 60607  
312.651.7350  
[www.LLS.org/il](http://www.LLS.org/il)

**The Leukemia Research Foundation**

3520 Lake Avenue, Suite 202  
Wilmette, IL 60091  
(847) 424-0600  
[www.leukemia-research.org](http://www.leukemia-research.org)

**The National Children's cancer Society (NCCS)**

500 North Broadway, Suite 1850  
St. Louis, MO 63102  
(341) 241-1600  
<http://www.thenccs.org/>

**Multiple Myeloma Research Foundation**

383 Main Avenue, 5th Floor  
Norwalk, CT 06851

(203) 229-0464  
[www.themmr.org](http://www.themmr.org)

**Stupid Cancer**

Online/National  
New York, NY  
<http://stupidcancer.org/>

**The Myelodysplastic Syndromes Foundation**

4573 S. Broad Street, Suite 150  
Yardville, NJ 08620  
(800) MDS-0839  
[www.mds-foundation.org](http://www.mds-foundation.org)

**The SAM Fund**

Online/National  
Boston, MA  
[www.thesamfund.org/](http://www.thesamfund.org/)

**Wooden Nickels**

PO Box 5287  
Evanston, IL 60204  
(888) 842-2654  
[www.nowoodennickels.org](http://www.nowoodennickels.org)

**Patient Access Network Foundation**

PO Box 221858  
Charlotte, NC 28222  
(866) 316-7263  
[www.panfoundation.org](http://www.panfoundation.org)

**Other Useful Resources**

**Association of Cancer Online**

Resources  
New York, NY  
[www.acor.org](http://www.acor.org)

### **3 Little Birds 4 Life**

Online/National  
P.O. Box 187  
Collinsville, IL 62234  
[www.3littlebirds4life.org](http://www.3littlebirds4life.org)  
(888) 370-8885

### **BMT Information Network**

2310 Skokie Valley Road, Suite 104  
Highland Park, IL 60035  
(847) 433-3313  
[www.bmtinfont.net](http://www.bmtinfont.net)

### **Cancer and Careers**

286 Madison Avenue, 19th Floor  
New York, NY 10017  
(212) 685-5955  
[www.cancerandcareers.org](http://www.cancerandcareers.org)

### **Cancer Legal Resource Center**

227 W. Monroe Street, 44th Floor  
Chicago, IL 60606  
(866) 843-2572  
[www.cancerlegalresourcecenter.org](http://www.cancerlegalresourcecenter.org)

### **Care Pages**

345 Hudson Street, 16th Floor  
New York, NY 10014  
(646) 728-9500  
[www.carepages.com](http://www.carepages.com)

### **Caring Bridge**

1715 Yankee Doodle Road, Suite 301  
Eagan, MN 55121  
(651) 452-7940  
[www.caringbridge.org](http://www.caringbridge.org)

### **Cleaning For A Reason**

211 S. Stemmons, Suite G  
Lewisville, TX 75067  
(877) 337-3348  
[www.cleaningforareason.org](http://www.cleaningforareason.org)

### **Imerman's Angels**

205 W. Randolph 19th floor  
Chicago, IL 60606  
(877) 274-5529  
[www.imermanangels.org](http://www.imermanangels.org)

### **Lotsa Helping Hands**

34 Washington Street, Suite 310  
Wellesley Hills, MA 02481  
[www.lotsahelpinghands.com](http://www.lotsahelpinghands.com)

### **Lymphoma Research Foundation**

134 N. LaSalle Street, Suite 1950  
Chicago, IL 60602  
(312) 263-1717  
[www.lymphoma.org](http://www.lymphoma.org)

### **National Coalition for Cancer Survivorship**

1010 Wayne Avenue, Suite 770  
Silver Spring, MD 20910  
(877) NCCS-YES  
[www.canceradvocacy.org](http://www.canceradvocacy.org)



**National Marrow  
Donor Program  
Be The Match**

3001 Broadway Street N.E.  
Minneapolis, MN 55413  
(888) 999-6743  
[www.bethematch.org](http://www.bethematch.org)

**Patient Advocate Foundation**

421 Butler Farm Road  
Hampton, VA 23666  
(800) 532-5274  
[www.patientadvocate.org](http://www.patientadvocate.org)

**National Patient  
Travel Center**

4620 Haygood Road, Suite 1  
Virginia Beach, VA 23455  
(800) 296-1217  
[www.patienttravel.org](http://www.patienttravel.org)

**FertileHOPE**

2201 E. Sixth Street  
Austin, TX 78702  
(877) 236-8820  
[www.fertilehope.org](http://www.fertilehope.org)

**Patient Access Network  
Foundation**

PO Box 221858  
Charlotte, NC 28222  
(866) 316-7263  
[www.panfoundation.org/](http://www.panfoundation.org/)

**The Myelodysplastic  
Syndromes Foundation, Inc**

Online/National  
Yardville, NJ  
<http://www.mds-foundation.org/>

**The Oncofertility  
Consortium**

303 E. Superior Street, Suite 10-121  
Chicago, IL 60611  
(312) 503-3378  
[www.oncofertility.northwestern.edu](http://www.oncofertility.northwestern.edu)

**The SAM Fund**

Online/National  
Boston, MA  
<http://www.thesamfund.org/>

**Second Act Wig Products**

3020 N. Lincoln Avenue  
Chicago, IL 60657  
(773) 525-2228  
[www.secondactchicago.com](http://www.secondactchicago.com)

**Illinois Department  
of Human Services**

100 S. Grand Avenue East  
Springfield, IL 62762  
(800) 843-6154  
[www.dhs.state.il.us](http://www.dhs.state.il.us)

**Centers for Medicare &  
Medicaid Services**

7500 Security Boulevard  
Baltimore, MD 21244  
(800) MEDICARE  
[www.medicare.gov](http://www.medicare.gov)

