

Highlights

- The decisions you make before you begin treatment are important and can impact your quality of life as you proceed through treatment.
- Insurance coverage and location should be considered as you choose a blood cancer specialist.
- A “hematologist-oncologist” is a doctor who specializes in treating people with blood cancers. Blood cancers are uncommon diseases, so it can be to your advantage to be treated by a doctor specially trained to focus on treating patients with blood cancers. There are many ways to find the blood cancer specialist who is right for you.
- Selecting a cancer treatment center may depend on several factors including your specific diagnosis, location and insurance coverage.

Introduction

Taking an active role in making decisions regarding your treatment can have a positive effect on your health and quality of life. One of your first choices as an active participant in your care is to either select a specialist to manage your treatment or to choose a treatment center. You may be seeking a blood cancer specialist or a treatment center because you:

- Are currently having lab and/or imaging tests to confirm or rule out a blood cancer diagnosis
- Have recently been diagnosed with a blood cancer and want to explore your treatment options
- Are in treatment but want to explore other options
- Have relapsed disease and want to get another medical (second) opinion about treatment
- Have consulted with specialists who provided differing recommendations and you want a second opinion.

Depending on the patients’ location, their knowledge of nearby facilities or even personal preference, some people choose a treatment center first, while others begin by choosing a doctor to manage their treatment. Some individuals may have the option to travel to another city or state for treatment, while others do not. In some cases, familiarity with a local treatment center may be important.

Whatever your situation, understanding which questions to ask, the issues to consider and the resources that are available will help you make informed choices.

This fact sheet provides general information. We encourage you to contact our Information Specialists by calling (800) 955-4572 or by emailing infocenter@LLS.org for help with your specific questions.

Insurance Coverage

For most people, insurance coverage is an important consideration when choosing a specialist or treatment center. Some insurance plans require a referral from your primary care doctor for a consultation with any type of specialist. They may also require that you choose from the plan’s in-network list of specialists and affiliated treatment centers. Check your insurance policy and speak to your insurance representative to understand the coverage provided by your plan. Make sure that you know whether your plan will cover getting a second or third medical opinion.

In some cases, when an insurance plan states that it will not cover a particular specialist or treatment center—for instance, if a specialist is not in the plan’s network—a letter from the patient’s doctor may help explain the medical necessity for the referral so the insurance company will agree to cover some or all of the costs. Some treatment centers have social workers, case managers or patient advocates who can help patients and families contact the insurance company and navigate the healthcare system.

The free LLS publication *Cancer and Your Finances* and the webpage www.LLS.org/finances provide more information on insurance coverage and other financial issues for people diagnosed with blood cancers.

Finding a Blood Cancer Specialist

Hematologists specialize in internal medicine with a subspecialty in hematology, the study of diseases of the blood. A “hematologist-oncologist” is a doctor who specializes in treating persons with blood cancers. A “board-certified” hematologist-oncologist is licensed to practice medicine, has additional education and training in hematology-oncology and has passed specialty medical board examinations. “Pediatric” hematologist-oncologists specialize in treating infants, children and adolescents with blood cancers.

Blood cancers are uncommon diseases, so it can be to your

advantage to be treated by a doctor specially trained to focus on treating patients with blood cancers. For this reason, many people with blood cancer choose a hematologist-oncologist to manage their treatment.

Some people with blood cancers are treated by other types of specialists, such as medical oncologists (internal medicine specialists with subspecialty training in diagnosing and treating cancer with chemotherapy and other drugs), internal medicine specialists or family practice specialists. If your doctor is not a blood cancer specialist, your treating doctor can work in consultation with a hematologist-oncologist.

There are several ways to find a specialist, including:

- Asking your primary care doctor for a recommendation
- Contacting your community cancer center
- Reaching out to doctor and/or insurance referral services
- Calling an Information Specialist at LLS
- Using online doctor-finder resources, such as
 - The American Board of Medical Specialties (ABMS) website, which offers a service to help patients find board-certified specialists
 - The American Medical Association (AMA) “DoctorFinder,” a resource available through the AMA website
 - “Find a Hematologist,” a service provided by the American Society of Hematology (ASH) to help match patients with hematologists in their area
 - “Find an Oncologist,” a service offered by Cancer.Net, the patient information website of the American Society of Clinical Oncology (ASCO)
 - “DocFinder,” a service offered by Administrators In Medicine (AIM) and the National Organization for State Medical & Osteopathic Board Executive Directors, which provides doctor licensing and disciplinary information and is available through the AIM website.

Please see the *Resources for Finding a Specialist* section on page 5 for information on how to contact the organizations mentioned above.

Questions to Help You Choose a Specialist

When you are speaking with a doctor and any information is unclear, ask him or her to slow down or to explain things in another way. Remember that it is your right to be informed and the doctor’s responsibility to communicate clearly with you. Specific questions you may want to ask include:

- Are you board certified and licensed?
- Are you a member of any professional societies?
- How much experience do you have treating patients with my disease?
- Is your hospital, university, center or clinic accredited and experienced in treating blood cancers?
- How long should I expect to wait for appointments or return of my phone calls?
- Will there be nurses, social workers and case managers available to help me with support and quality-of-life concerns?
- Would you recommend that I speak with any other hematologist-oncologists?
- When should I call you? What questions should I call my family doctor for?
- What is the best way to contact you?
- How do I contact you at night? On weekends? On holidays?

For a printable list of these questions, visit www.LLS.org/whattoask and click on “Choosing a Specialist.” You can also contact an Information Specialist at (800) 955-4572 or email infocenter@LLS.org to request a copy.

Depending on your treatment needs, insurance coverage, and family and work considerations, you may want to have consultations with a number of doctors. Taking notes or recording the meeting (ask the specialist if he or she minds) may also be helpful.

You may also want to have a family member or friend accompany you to your appointment(s) to help ask questions, take notes and lend support. This can make the visit less stressful and may help you remember what the specialist says more clearly.

Do You Want to Get a Second Opinion?

It is very important to make sure you have the right diagnosis before you begin or continue with treatment. Some people want to get a second or third medical opinion after receiving a diagnosis and before beginning or continuing treatment. However, for patients with acute illnesses (such as certain aggressive types of lymphoma or leukemia), delaying therapy in order to have several consultations is generally not a good idea.

Getting a second opinion allows another specialist to review your test results and medical history and help:

- Answer your questions
- Present other treatment options for you to consider

- Provide reassurance that you have been thorough in seeking care.

If you are unsure whether a specific doctor or treatment center is right for you, it is advisable to get another opinion. The following questions can help you determine whether to get another medical opinion. All or some of these issues may be important to you, and you may want to discuss them with your family doctor, family or friends as well.

- Am I satisfied with the specialist's qualifications and experience?
- Has the specialist explained my diagnosis and treatment options in a way that I understand?
- Am I satisfied with the expertise of the medical professionals involved in determining my diagnosis, including that of the hematopathologist? (A hematopathologist is a medical doctor who specializes in examining blood and bone marrow.)
- Does this specialist's approach, treatment plan and treatment center meet my needs regarding insurance coverage and/or location?
- Do I feel comfortable asking all of my questions?
- Does the specialist take the time to address my concerns respectfully and completely, or do I feel rushed?
- Are the doctor's staff members well-informed and courteous? Are they available to assist me with billing concerns, medication questions, referrals to support organizations and other information?

The free LLS publication *Each New Day* provides additional information on finding a second opinion. You can also go to www.LLS.org/whattoask and click on "Second Opinion Consultation" or contact an Information Specialist by phone at (800) 955-4572 or by email at infocenter@LLS.org for more information on this topic.

Choosing a Treatment Center

Selecting a cancer treatment center may depend on several factors including your specific diagnosis, location and insurance coverage. You will want to choose an accredited treatment center with the medical expertise to provide the type(s) of treatment you will need. An accredited treatment center is an organization that is evaluated against national standards. Most healthcare organizations and programs in the United States are evaluated for accreditation by the Joint Commission on Accreditation of Healthcare Organizations. Receiving accreditation from The Joint Commission means that an organization complies with The Commission's standards and strives to improve the care and services it provides. To review The Joint Commission's performance

reports for a participating institution, click on "Quality Check" at the top right corner of The Joint Commission's webpage (www.jointcommission.org).

Types of Cancer Treatment Centers

The different types of treatment centers include local hospitals or community cancer centers, university-affiliated hospitals and comprehensive cancer centers.

NCI-Designated Cancer Centers – The National Cancer Institute (NCI) is one of eight agencies that make up the National Institutes of Health (NIH). The NCI coordinates the National Cancer Program, which conducts and supports research and training and provides a wealth of information. The NCI also supports a national network of cancer centers, each of which must meet scientific, organizational and administrative criteria to be recognized by the institute. There are two types of cancer centers recognized by the NCI: NCI-designated comprehensive cancer centers and NCI-designated cancer centers.

An *NCI-designated comprehensive cancer center* offers the most recent advances in cancer diagnosis and treatment, including clinical trials. The center must demonstrate research in each of three major areas: laboratory, clinical, and population-based research. In addition, a comprehensive center must also demonstrate professional and public education and outreach capabilities, including the distribution of clinical and public health advances in the communities it serves.

An *NCI-designated cancer center* offers the most recent advances in cancer diagnosis and treatment, including clinical trials. The center must demonstrate scientific leadership, resources, and capabilities in laboratory, clinical, or population science, or some combination of these three components. It must also demonstrate reasonable research in the scientific areas it chooses.

University-Affiliated Hospitals or Centers – These centers are affiliated with a university or medical school and provide training for medical students. They may be NCI-designated and are likely to offer up-to-date cancer treatment and care, have a support staff and have a unit or associated center that performs stem cell transplantation.

Community Cancer Centers or Local Hospitals – There are many very good community cancer centers and hospitals that also provide patient care. Patients may choose to receive treatment at one of these centers because of the convenience of having their treatment close to home, or because they already know and are comfortable with the healthcare professionals who practice there. If the local treatment center or hematologist-oncologist is affiliated with the Community Clinical Oncology Program, known as

“CCOP” (an NCI-designated program by which local and community oncologists collaborate with NCI researchers), patients may be able to receive NCI-sponsored treatments, including access to clinical trials, at the local center.

If the local center is not affiliated with the NCI and/or a university or medical school, it is important to ask the local specialist if he or she will be able to consult with area university specialists or NCI researchers before and during the course of treatment.

Finding a Treatment Center

There are several ways to find a treatment center, including:

- Asking your primary care doctor for a referral
- Contacting doctor and/or insurance referral services
- Calling an Information Specialist at LLS
- Contacting any of the following organizations:
 - The Association of Community Cancer Centers (ACCC), which provides information on more than 670 community cancer centers
 - The Agency for Healthcare Research and Quality (AHRQ), which provides information on health-related topics and links to resources
 - “Find an Approved Cancer Program Near You,” a service offered by the Commission on Cancer (CoC) that is available through the American College of Surgeons website
 - The Joint Commission, which provides information on more than 15,000 health care organizations and programs in the United States
 - The National Cancer Institute (NCI) website, which provides a listing of all NCI-designated comprehensive cancer centers across the country
 - The National Marrow Donor Program (NMDP) website, which offers information on transplant centers in the United States.

More information on these organizations, including detailed contact information, can be found in *Resources for Finding a Treatment Center* on page 6.

Questions to Help You Choose a Treatment Center

- Is care at the treatment center covered by my insurance plan?
- Does my primary care doctor or hematologist-oncologist have confidence in this treatment center?

- What type of accreditation does the treatment center have? Do the treatment center and the staff have experience in treating my specific type of blood cancer?
- Does the center offer the most current treatments available?
- Does the center participate in clinical trials related to my diagnosis?
- Are adequate support staff (nurses, social workers, case managers, patient advocates) available?
- Will I see the same support staff members at each visit?
- Is there a pharmacy on the premises or nearby?
- If a stem cell transplant is part of the treatment plan, is this center experienced in performing the type of stem cell transplant I will need?
- Can I speak to other cancer patients who are being treated or were treated at this center?

For a printable list of these and other questions related to treatment, please go to www.LLS.org/whattoask and click on “Treatment Options.” You can also contact an Information Specialist at (800) 955-4572 or email infocenter@LLS.org to request copies.

We’re Here to Help

LLS is the world’s largest voluntary health organization dedicated to funding blood cancer research, education and patient services. LLS has chapters throughout the country and in Canada. To find the chapter nearest to you, visit our website at www.LLS.org or contact:

The Leukemia & Lymphoma Society

3 International Drive, Suite 200

Rye Brook, NY 10573

Contact an Information Specialist at (800) 955-4572

Email: infocenter@LLS.org

LLS offers free information and services for patients and families touched by blood cancers. The following lists various resources available to you. Use this information to learn more, to ask questions, and to make the most of your healthcare team’s knowledge and skills.

Consult with an Information Specialist. Information Specialists are master’s level oncology social workers, nurses and health educators. They offer up-to-date disease and treatment information. Language services are available. For more information, please:

- Call: (800) 955-4572 (M-F, 9 a.m. to 9 p.m. EST)
- Email: infocenter@LLS.org

- Live chat: www.LLS.org
- Visit: www.LLS.org/information specialists

Free Materials. LLS offers free education and support publications that can either be read online or downloaded. Free print versions can be ordered. For more information, please visit www.LLS.org/publications.

Información en Español (LLS information in Spanish). For more information, please visit www.LLS.org/espanol.

Telephone/Web Education Programs. LLS offers free telephone/web education programs for patients, caregivers and healthcare professionals. For more information, please visit www.LLS.org/programs.

Co-Pay Assistance Program. LLS offers insurance premium and medication co-pay assistance for certain eligible patients. For more information, please:

- Call: (877) 557-2672
- Visit: www.LLS.org/copay.

Online Blood Cancer Discussion Boards and Chats. Online discussion boards and moderated online chats can provide support and help cancer patients to reach out to others in similar circumstances, and share information. For more information, please visit www.LLS.org/chat or www.LLS.org/discussionboard.

LLS Chapters. LLS offers community support and services in the United States and Canada including the *Patti Robinson Kaufmann First Connection Program* (a peer-to-peer support program), in-person support groups, and other great resources. For more information about these programs or to contact your chapter, please:

- Call: (800) 955-4572
- Visit: www.LLS.org/chapterfind.

Clinical Trials (Research Studies). New treatments for patients are ongoing. Patients can learn about clinical trials and how to access them. For more information, please:

- Call: (800) 955-4572 to speak with our LLS Information Specialists who can help conduct clinical-trial searches
- Visit: www.LLS.org/clinicaltrials.

Advocacy. LLS enlists volunteers to advocate for policies and laws to speed new treatments and improve access to quality medical care. For more information, please:

- Call: (800) 955-4572
- Visit: www.LLS.org/advocacy.

Resources for Finding a Specialist

American Board of Medical Specialties (ABMS) (312) 436-2600

www.abms.org

The ABMS offers a free online resource for patients to determine if a doctor is board certified. The online verification service allows visitors to conduct searches by doctor name or area of certification and state name. On the ABMS site, go to the “Certification Matters Service” under the “Verify Certification” tab. Here patients can research the Board Certification status of doctors, including whether they are meeting ABMS Maintenance of Certification requirements.

American Medical Association (AMA)

www.ama-assn.org

AMA’s “DoctorFinder” provides basic professional information about a large number of licensed doctors in the United States. On the right side of the main site, click “Patients” and then scroll down from the list of “Featured Resources” and click on “DoctorFinder.” Searches can be conducted by doctor name and location or by specialty and location.

American Society of Hematology (ASH)

(202) 776-0544

www.hematology.org

ASH is dedicated to promoting education, research, clinical care, training and advocacy in hematology. The ASH website offers the service “Find a Hematologist” to help match patients with hematologists in their area. On the main site, click on the “Find a Hematologist” link midway down the page on the left side.

Cancer.Net/ASCO

(888) 651-3038

www.cancer.net

Cancer.Net is the patient information website of the American Society of Clinical Oncology (ASCO). More than 25,000 oncology practitioners belong to ASCO, representing all oncology disciplines (medical, radiation, and surgical oncology) and other subspecialties. Members include doctors and healthcare professionals participating in approved oncology training programs. Click on “Find a Cancer Doctor” on the left side of the page. Searches can be conducted by doctor name, location or specialty.

Administrators In Medicine (AIM) – National Organization for State Medical & Osteopathic Board Executives

(919) 573-5445

www.docboard.org

AIM's website provides "DocFinder," an online searchable database containing doctor licensing and disciplinary information for doctors in some states across the United States. To conduct a search, click on "DocFinder Searches" on the left navigation bar. Searches can be conducted by doctor name and state. The AIM website also provides links to individual state search websites whose licensing data are not available through "DocFinder."

Resources for Finding a Treatment Center

American College of Surgeons

(800) 621-4111

www.facs.org

The American College of Surgeons' multidisciplinary program called the "Commission on Cancer" (CoC) is dedicated to improving survival and quality of life for cancer patients through prevention, research and the monitoring of comprehensive quality care and the setting of standards for cancer programs. The CoC provides a database of approved cancer programs throughout the United States. From the website's home page see "Quality Programs," then "Cancer," then "Accredited Cancer Programs," and then, on the left side of the page, "Find a CoC-Accredited Program."

Association of Community Cancer Centers (ACCC)

(301) 984-9496

www.accc-cancer.org

The ACCC website provides information on over 670 community cancer centers and oncology private practices. On the main site, click on "Find a Cancer Program."

Joint Commission on Accreditation of Healthcare Organizations

(630) 792-5800

www.jointcommission.org

The Joint Commission on Accreditation of Healthcare Organizations is an organization that develops standards for, evaluates and accredits more than 15,000 healthcare organizations and programs in the United States. To review The Joint Commission's performance reports for a participating institution, click on the link "Quality Check" on the top right side of The Joint Commission's webpage.

National Cancer Institute (NCI) Cancer Center Programs

(240) 276-5600

www.cancercenters.cancer.gov/Center/CancerCenters

The National Cancer Institute (NCI) is the U.S. government's main agency for cancer research and training, and a component of the National Institutes of Health (NIH). The NCI Cancer Centers Program website provides a listing of all NCI-designated comprehensive cancer centers and clinical cancer centers across the country. Cancer center lists can be found on the top left side of the page and are arranged alphabetically and by state.

National Marrow Donor Program (NMDP)

(800) MARROW2 (627-7692)

www.bethematch.org

The "Choosing a transplant center" page at the NMDP website provides details, statistics and outcome data for more than 170 NMDP transplant centers in the United States. Click on "Choosing a transplant center" under the "For Patients and Families" tab.

Patient Resource Cancer Guide

(800) 497-7530

www.patientresource.net

The "Patient Resource Cancer Guide" is a free publication for newly diagnosed cancer patients and cancer patients with relapsed or refractory disease. This comprehensive resource helps patients and their families map the cancer journey. To request a free copy, call the number above or click on "Order Your Guides Here" in the red block on the bottom right side of the website.

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