

Choosing a Blood Cancer Specialist or Treatment Center

No. 6 in a series providing the latest information for patients, caregivers and healthcare professionals

Taking an active role in treatment decision making 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 select a physician 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 opinion about treatment
- Have consulted with two specialists who provided differing recommendations and you want another medical opinion.

Some people choose a treatment center first, while others begin by choosing a physician to manage the treatment. Some individuals have the option to travel to another city or state for treatment, while others do not. Whatever your situation is, knowing the questions to ask, issues to consider and resources that are available will help you make informed choices.

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

Health Plan Coverage

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

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

The free LLS booklet *Financial Health Matters* and the Web page at www.LLS.org/insurance provide more information on health plan coverage and other financial issues for people diagnosed with blood cancers.

Finding a Blood Cancer Specialist

This section on finding a blood cancer specialist includes resources and a list of questions to help you choose a specialist. *Finding a Treatment Center* begins on page 6 and includes resources and a list of issues to consider as you select a treatment center.

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

Blood cancers are uncommon diseases, so it can be an advantage to be treated by a physician who focuses on treating patients with blood cancers. For this reason, many people with blood cancer choose a hematology-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 physician is not a blood cancer specialist, your treating physician can work in consultation with a board-certified hematology-oncologist.

Finding a Blood Cancer Specialist

There are several ways to find a specialist, including

- Asking your primary care physician whom he or she would use
- Contacting your community cancer center
- Calling your local medical society
- Reaching out to physician and/or health plan referral services
- Calling LLS for a list of cancer centers or going to www.LLS.org and clicking on “Cancer Centers”
- Using online physician-finder resources, such as

- The American Board of Medical Specialties (ABMS) Web site, which offers a service to help patients find board-certified specialists
- The American Medical Association (AMA) “DoctorFinder,” a resource available through the AMA Web site
- “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 Web site of the American Society of Clinical Oncology
- “DocFinder,” a service offered by Administrators In Medicine (AIM) and the National Organization for State Medical & Osteopathic Board Executive Directors, which provides physician licensing and disciplinary information and is available through the AIM Web site.

Please see the *Resources for Finding a Specialist* section on page 8 for information on how to contact the organizations mentioned above.

Questions to Help You Choose a Specialist

When you are speaking with the physician, ask him or her to slow down or to explain things in another way if anything is unclear. Remember that it is your right to communicate with your physician and the physician’s responsibility to communicate 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 would I usually have 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 needs and quality-of-life concerns?
- Are there any other hematology-oncologists with whom you would recommend I speak?
- What types of things should I call you about? What types of things should I call my family doctor about?
- How should I contact you with questions?
- How do I contact you at night? On weekends? On holidays?

For a printable list of these questions, please go to www.lls.org/whattoask and click on “Choosing a Specialist.” You can also contact the Information Resource Center at (800) 955-4572 or email info@LLS.org to request a copy.

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

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

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.

Another specialist can review your test results and medical history and help

- Answer your questions
- Present other options to consider
- Provide reassurance that you have been thorough in seeking care.

If you have any concerns about whether a specific physician or treatment center is right for you, it is advisable to get another opinion. The following list of questions can help you evaluate whether to get another medical opinion. All or some of these issues may be important to you. You may want to discuss these questions with your family physician, a friend or family member 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 them?
- 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 health plan coverage and/or location?
- Do I feel comfortable asking all the questions I have?
- Does the specialist take the time to address my concerns respectfully and completely or do I feel rushed?
- Do the physician's staff members seem 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 booklet *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 Consultations" or contact the Information Resource Center by phone at (800) 955-4572 or by email at info@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, area of residence and healthcare coverage. You will want to choose one that has the medical expertise to provide the type(s) of treatment you will need and is an accredited treatment center. Participating in an accreditation process means that an organization is evaluated against national standards. Most healthcare organizations and programs in the United States follow an evaluation process so that they can be accredited by the Joint Commission on Accreditation of Healthcare Organizations. Receiving accreditation from The Joint Commission means that an organization complies with The Joint Commission's standards and makes efforts to improve the care and services it provides. To review The Joint Commission's performance reports for a participating institution, click on the link "Quality Check" at the top right corner of The Joint Commission's Web page.

Many comprehensive cancer centers, clinical cancer centers and community clinical-oncology program centers are "NCI-designated," meaning they are evaluated every three to five years by the National Cancer Institute (NCI). These centers are likely to offer the newest treatment options.

Types of Cancer Treatment Centers

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 health information. The NCI also supports a national network of cancer centers, which must meet scientific, organizational and administrative criteria in order 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.

NCI-designated comprehensive cancer centers offer the most recent advances in cancer diagnosis and treatment, including participation in cancer clinical trials. These centers also provide community outreach and education programs about cancer. The benefits of choosing one of these centers include up-to-date treatment, experienced healthcare professionals, access to clinical trials and a unit or associated center that performs stem cell transplantation.

NCI-designated clinical cancer centers also offer the most up-to-date advances in cancer diagnosis and treatment. These centers offer experienced healthcare professionals access to clinical trials, and access to a unit or associated center that performs stem cell transplantation.

University-Affiliated Hospitals or Centers. These centers are affiliated with a university or medical school and provide training to medical students. They may be NCI-designated and are likely to offer up-to-date cancer treatment and care, have a supportive 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, which are able to provide care. Patients may choose to receive treatment at one of these centers because of the convenience of being able to get 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 hematology-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.

Patients may also choose to travel to another city or state if there are no NCI-designated centers near where they live. When travel is not an option and 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 or during the course of treatment.

Finding a Treatment Center

There are several ways to find a treatment center, including

- Asking your primary care physician for a referral
- Reaching out to physician and/or health plan referral services
- Calling LLS for a list of cancer centers or going to www.LLS.org and clicking on “Cancer Centers”
- 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 Web site
 - 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) Web site, which provides a listing of all NCI-designated comprehensive cancer centers across the country
 - The National Marrow Donor Program (NMDP) Web site, 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 9.

Questions to Help You Choose a Treatment Center

- Is care at the treatment center covered by my health plan?
- Does my primary care physician or hematology-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 (research studies) for my diagnosis?
- Are adequate support staff (nurses, social workers, case managers, patient advocates) available?
- Will I see the same professional 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.” You can also contact the Information Resource Center at (800) 955-4572 or email info@LLS.org to request copies.

We’re Here to Help

The Leukemia & Lymphoma Society (LLS) is the world’s largest voluntary healthcare 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 you, visit our Web site, www.LLS.org, or contact

The Leukemia & Lymphoma Society

1311 Mamaroneck Avenue

White Plains, NY 10605

Information Resource Center (800) 955-4572

Email: infocenter@LLS.org

Callers to the Information Resource Center may speak directly with an information specialist, Monday to Friday, 9 a.m. to 6 p.m., ET. You may also contact an information specialist by clicking on “Live Help” (10 a.m. – 5 p.m.) at www.LLS.org or by sending an email. Information specialists can answer general questions about diagnosis and treatment options, offer guidance and support and assist with clinical trial searches for leukemia, lymphoma, myeloma, myelodysplastic syndromes and myeloproliferative diseases. The Web site, www.LLS.org, has information about how to find a clinical trial, including a link to TrialCheck®, a clinical trials search service provided by LLS. For questions about the Co-Pay Assistance Program, please contact us by phone at (877) 557-2672 or by email at copay@LLS.org. LLS also provides fact sheets and booklets that can be ordered via (800) 955-4572 or through the “Free Materials” on the Web site.

Resources for Finding a Specialist

American Board of Medical Specialties (ABMS)

(866) ASK-ABMS (275-2267)

www.abms.org

The ABMS offers three free resources for patients to determine if a doctor is board certified. Patients can call the certification and verification service line at (866) ASK-ABMS (275-2267). The online verification service allows visitors to conduct searches by physician name or area of certification and state name. On the ABMS site, click on “How We Help You” on the left-side navigation, then click on “Consumers.” In the “Consumers” menu, click on “Find a Board Certified Specialist Here.” Visitors must register in order to conduct a search. The ABMS publication *The Official ABMS Directory of Board Certified Medical Specialists* provides current professional and biographical information on physicians who have completed certification requirements within their respective medical specialty boards. The ABMS directory is available in many medical and public libraries.

American Medical Association (AMA)

www.ama-assn.org

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

American Society of Hematology (ASH)

www.hematology.org

ASH is dedicated to promoting education, research, clinical care, training and advocacy in hematology. The ASH Web site 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 on the lower left-hand corner of the page.

Cancer.Net/ASCO

(571) 483-1300 (ASCO line)

www.asco.org/portal/site/patient

Cancer.Net is the patient information Web site 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 physicians and healthcare professionals participating in approved oncology training programs. Click on “Find an Oncologist” on the left navigation bar. Searches can be conducted by physician name, location or specialty.

**Administrators In Medicine (AIM) – National Organization for State Medical & Osteopathic Board
Executive Directors**
www.docboard.org

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

Resources for Finding a Treatment Center

American College of Surgeons
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 Web site's home page see "Divisions and Programs," then "Cancer Programs," then click on "Find an Approved Cancer Program Near You."

Association of Community Cancer Centers (ACCC)
(301) 984-9496
www.accc-cancer.org

The ACCC Web site 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" at the top right corner of The Joint Commission's Web page.

National Cancer Institute (NCI) Cancer Center Programs

(800) 4CANCER (422-6237)

cancercenters.cancer.gov/

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 Web site provides a listing of all NCI-designated comprehensive cancer centers and clinical cancer centers across the country. Cancer center lists are arranged alphabetically and by state.

National Marrow Donor Program (NMDP)

(800) MARROW2 (627-7692)

www.marrows.org/PATIENT/Plan_for_Tx/Choosing_a_TC

The "Choosing a Transplant Center" page at the NMDP Web site provides details on transplant centers, statistics and outcome data for more than 170 NMDP transplant centers in the United States. Click on the "U.S. NMDP Transplant Centers" link for a listing of centers arranged by state.

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