



**The Leukemia &
Lymphoma Society**[®]

Fighting Blood Cancers

The CLL Guide

Information for Patients and Caregivers

LEUKEMIA

LYMPHOMA

MYELOMA

CHRONIC LYMPHOCYTIC LEUKEMIA



A Message from John Walter
President and CEO of The Leukemia & Lymphoma Society

The Leukemia & Lymphoma Society (LLS) is committed to bringing you the most up-to-date blood cancer information. We know how important it is for you to have an accurate understanding of your diagnosis, treatment and support options. With this knowledge, you can work with members of your oncology team to move forward with the hope of remission and recovery.

Our vision is that one day the great majority of people who have been diagnosed with chronic lymphocytic leukemia will be cured or they will be able to manage their illness with good quality of life. We hope that the information in this booklet will help you along your journey.

LLS is the world's largest voluntary health organization dedicated to funding blood cancer research, education and patient services. Since its founding in 1949, LLS has invested more than \$600 million in research specifically targeting blood cancers. We will continue to invest in research for cures and programs and services that improve the quality of life of patients and their families.

We wish you well.

A handwritten signature in black ink, appearing to read "J. Walter". The signature is fluid and cursive, with a large loop at the beginning.

John Walter
President and CEO

Reach Out to Our Information Resource Center

The Leukemia & Lymphoma Society's (LLS) Information Resource Center provides patients, families and healthcare professionals with the latest information on leukemia, lymphoma and myeloma. Our information specialists – master's level oncology professionals – are available by phone Monday through Friday, 9 am to 6 pm (ET).

Call 800.955.4572 for a complete directory of our patient services programs. Callers may request a language interpreter.



**The Leukemia &
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Fighting Blood Cancers

www.lls.org

Co-Pay Assistance

LLS's Co-Pay Assistance Program helps blood cancer patients cover the costs of private and public health insurance premiums, including Medicare and Medicaid, and co-pay obligations. Support for this program is based on the availability of funds by disease diagnosis. For more information, call 877.557.2672 or visit www.lls.org/copay.

Introduction

Chronic lymphocytic leukemia (CLL) is a type of cancer. This is a hopeful time for people with CLL. Many people with CLL live good-quality lives for years with medical care. There are a number of treatments for CLL. In recent years new therapies have been approved and other possible new treatments are being studied in clinical trials. Progress toward a cure is under way.

CLL is the most common type of leukemia in adults.

In 2009, about 85,710 people in the United States are living with CLL or are in remission.

The CLL Guide is for people with CLL and others who want basic information about the disease. Many people find that it helps to know the questions to ask about choosing a specialist and about treatment. The *Guide* includes suggested questions to ask your doctor (see the pocket on the inside back cover). For a list of other Healthcare Question Guides you can print, go to www.LLS.org/whattoask and click on “Healthcare Question Guides.” Or contact the Information Resource Center (IRC) for copies.

Tell Us What You Think. We hope the information helps you. Please tell us what you think at www.LLS.org/publicationfeedback. Click on “LLS Disease & Treatment Publications - Survey for Patients, Family and Friends” on the Web page.

LLS Has Other Free Materials. You may want to learn more about CLL after reading the *Guide*. Free LLS disease, treatment and support materials are available in print and at www.LLS.org/freematerials. Materials that may be of interest to you are listed in the *Guide* next to this icon:



To order free LLS booklets, contact us at www.LLS.org or (800) 955-4572.

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Check **Medical Terms** for words that are new to you. Or contact the **Information Resource Center** at www.LLS.org or (800) 955-4572.

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Some words in the *Guide* may be new to you. Check *Medical Terms* beginning on page 28. Or call the Information Resource Center at (800) 955-4572.

Want More Information?



You can view, print or order the free LLS booklets *Understanding Leukemia* and *Chronic Lymphocytic Leukemia* for more information. Go to www.LLS.org/freematerials or contact the Information Resource Center for copies.

This LLS guide about CLL is for information only. LLS does not give medical advice or provide medical services.

Join us for the latest information on CLL during our **free teleconferences**. Go to www.LLS.org or call **(800) 955-4572**.

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Part 1 – Understanding CLL

Leukemia is the general term for some different types of blood cancer. CLL is one of four main types of leukemia.

About Marrow, Blood and Blood Cells

The information on this page about normal blood and marrow may help you understand the CLL information in the rest of the *Guide*.

Marrow is the spongy center inside of bones where blood cells and immune cells are made.

Blood cells are made in the marrow. They begin as stem cells. Stem cells become red cells, white cells and platelets in the marrow. Then the red cells, white cells and platelets enter the blood.

Platelets prevent bleeding by forming plugs that help stop bleeding at the site of an injury.

Red cells carry oxygen around the body. When the number of red cells is below normal, the condition is called “anemia.” Anemia may make you feel tired or short of breath. It may make your skin look pale.

White cells fight infection in the body. There are two major types of white cells: germ-eating cells (neutrophils and monocytes) and lymphocytes (B cells, T cells and natural killer (NK) cells).

Plasma is the liquid part of the blood. It is mostly water. It also has some vitamins, minerals, proteins, hormones and other natural chemicals in it.

The Immune System

The immune system is the body's defense against infection.

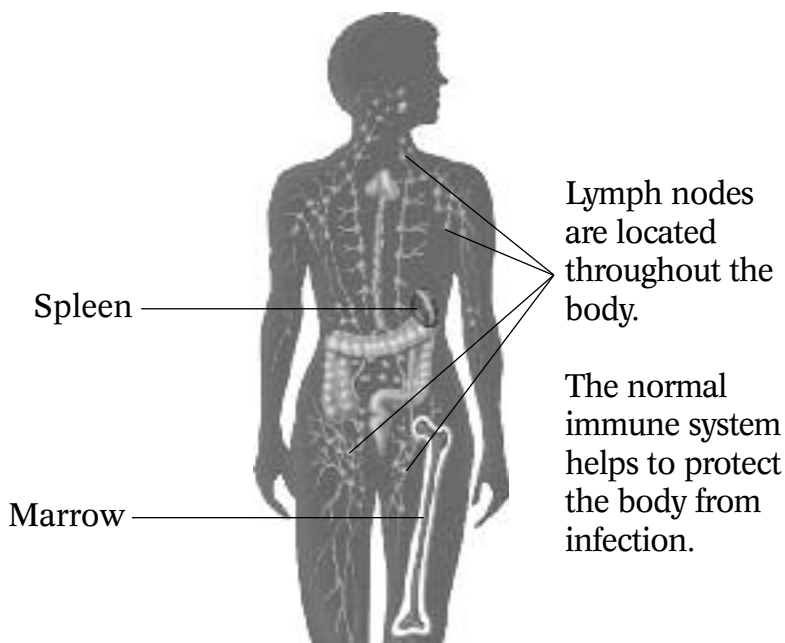
The marrow and the lymphocytes are part of the immune system.

Here are some other parts of the immune system:

Lymph nodes are bean-sized collections of lymphocytes found throughout the body. There are about 600 lymph nodes throughout the body—in the neck, armpits, chest, abdomen, groin and some other parts of the body. Lymphatic vessels connect the lymph nodes. They contain lymph, a fluid that carries lymphocytes.

The spleen is an organ found on the left side of the body, near the stomach. It contains lymphocytes and removes worn-out cells from the blood.

Some Parts of the Immune System



To order free LLS booklets, contact us at www.LLS.org or (800) 955-4572.

About CLL

CLL is a type of cancer that begins in the bone marrow. It starts with a change to a lymphocyte (a type of cell that fights infection). CLL cells do not fight infection like normal lymphocytes do.

Over time, CLL cells replace normal lymphocytes in the marrow and lymph nodes. If there is a high number of CLL cells in the marrow they may crowd out the normal blood-forming cells (red cells, white cells and platelets).

Some people have CLL that grows slowly. They do not need drug therapy right away. Other people have CLL that grows faster. They do need drug therapy once their CLL is diagnosed. (Information about treatment begins on page 12.)

Doctors do not know what causes the cell-change that leads to CLL.

There is no way to prevent CLL. You can't catch CLL from someone else. It's not common, but in some families more than one blood relative has CLL. Doctors are studying why some families have a higher rate of CLL.

Children do not get CLL. It's not a common disease in adults. But it is more common in people 60 years and older than in younger adults. The number of people with CLL starts to increase after age 50. A small number of people are diagnosed with CLL in their 30s and 40s.

Signs and Symptoms

A *sign* is a change in the body that the doctor sees in an exam or a lab test result. A *symptom* is a change in the body that a patient can see or feel.

Some people with CLL have no symptoms. These people may find out they have CLL after a regular medical checkup shows certain changes in the blood. CLL symptoms often develop slowly. People with CLL may have little or no change to their health for many years.

Some Signs and Symptoms of CLL

Tiring more easily. People may have less energy due to fewer healthy red cells and more CLL cells.

Shortness of breath. People may have shortness of breath while doing usual day-to-day activities. This is due to fewer healthy red cells and more CLL cells.

Swollen lymph nodes or spleen. High numbers of CLL cells can gather in the lymph nodes or spleen as the number of CLL cells grows.

Infections. People with a very high number of CLL cells building up in the marrow may have repeated infections of the skin or other parts of the body. This is because CLL cells cannot fight off infection as well as healthy lymphocytes.

Weight loss. Some people with CLL lose weight because they eat less and/or because they are using more energy.

People with CLL sometimes have other symptoms, such as aches, fever or night sweats. Many of the signs and symptoms of CLL are more likely to be caused by other illnesses. Most people with the signs and symptoms listed here do not have CLL.

Join us for the latest information on CLL during our **free teleconferences**. Go to www.LLS.org or call **(800) 955-4572**.

Diagnosis

The doctor orders blood tests to find the cause when a person has a high lymphocyte count.

Blood Tests. The diagnosis of CLL is usually made from blood cell counts and a blood cell examination.

- **Blood cell counts.** A person with CLL will have a high number of lymphocytes (high lymphocyte count). He or she may also have a low red cell count and a low platelet count.
- **Blood cell examination.** The CLL cells are usually examined with an instrument called a “flow cytometer.” The test is called “flow cytometry” or “immunophenotyping.” The test is done to find out if CLL is the reason for the high lymphocyte count. Flow cytometry also shows if the CLL is B-cell CLL or T-cell CLL. B-cell CLL is most common.

These are other lab tests for CLL:

Immunoglobulin Test. Doctors also check the “immunoglobulin” level in the blood. Immunoglobulins are proteins that help the body fight infection. People with CLL may have low levels of immunoglobulins. A low immunoglobulin level may be the cause of repeated infections. People who have low immunoglobulin levels and repeated infections may be given injections (shots) of immunoglobulins. Another name for immunoglobulin is “gamma globulin.”

Bone Marrow Tests. Bone marrow tests are not usually needed to make a CLL diagnosis. But, it's often helpful to have a "bone marrow aspiration" and a "bone marrow biopsy" before treatment begins. The results of these tests serve as a "baseline" that is used later on to assess the effects of treatment.

FISH. A test called "fluorescence in situ hybridization (FISH)" is used to see if there are changes to the chromosomes of the CLL cells. Every cell in the body has chromosomes that carry genes. Genes give the instructions that tell the cell what to do. About half of the people with CLL have CLL cells with chromosome changes. FISH may give doctors information about which people with CLL need more medical follow-up. FISH can be done with a sample of cells from blood or marrow.

How Are Blood and Bone Marrow Tests Done?

Blood Tests. Usually a small amount of blood is taken from the person's arm with a needle. The blood is collected in tubes and sent to a lab.

Bone Marrow Aspiration. A liquid sample of cells is taken from the marrow through a needle. The cells are then looked at under a microscope.

Bone Marrow Biopsy. A very small amount of bone marrow filled with marrow cells is removed through a needle. The cells are then looked at under a microscope.

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Blood and marrow tests may be done in the doctor's office or in a hospital. A bone marrow aspiration and a bone marrow biopsy are almost always done together. Both tests are done with a special needle. Some patients are awake for the procedure. They get medication first to numb the part of the body that will be used to take the sample of cells. This is usually the patient's hip bone. Some patients are sedated (asleep) for the procedure.

Tracking Your CLL Tests

These tips may help you save time and know more about your health:

- Ask your doctor why certain tests are being done and what to expect.
- Discuss test results with your doctor.
- Ask for and keep copies of lab reports in a file folder or three-ring binder. Organize test reports in date order.
- Find out if and when follow-up tests are needed.
- Mark appointments that are coming up on your calendar.



You can view, print or order the free LLS booklet *Understanding Lab and Imaging Tests* to learn more about lab tests and what to expect. Go to www.LLS.org/freematerials or contact the Information Resource Center for a copy.

Part 2 – Treatment

Choosing a Specialist

Choose a doctor who specializes in treating CLL and knows about the most up-to-date treatments. This type of specialist is usually called a “hematology oncologist.” Or your local cancer specialist can work with a CLL specialist.

Ways to Find a CLL Specialist

- Ask your primary care doctor
- Contact your community cancer center
- Reach out to health plan referral services
- Call LLS for a list of cancer centers or go to www.LLS.org and click on “Cancer Centers”
- Use online doctor-finder resources, such as
 - The American Medical Association’s (AMA) “DoctorFinder”
 - The American Society of Hematology’s (ASH) “Find a Hematologist”

See *Choosing a Blood Cancer Specialist or Treatment Center* for information on how to contact these organizations and others.



You can view, print or order the free LLS fact sheet *Choosing a Blood Cancer Specialist or Treatment Center* at www.LLS.org/freematerials. Or contact the Information Resource Center for a copy.

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Goals of Treatment

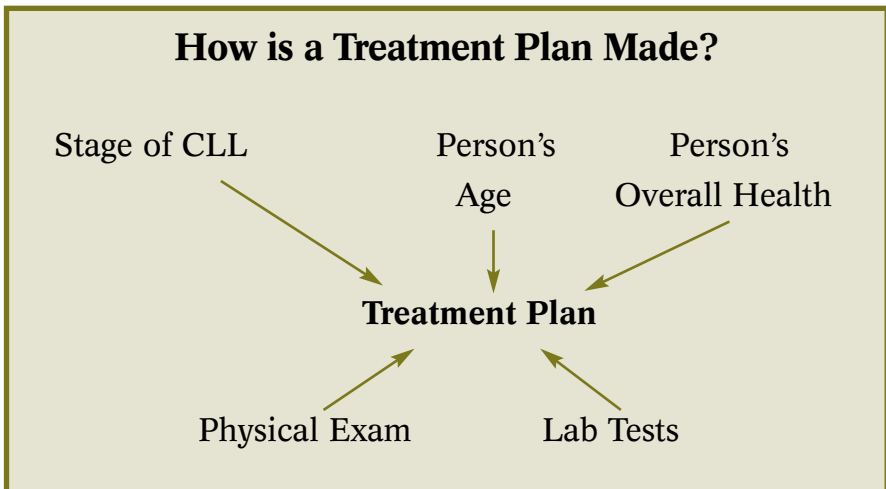
The goals of CLL treatment are to

- Slow the growth of the CLL cells
- Provide long periods of remission (when there are no signs of CLL and/or people feel well enough to carry on their day-to-day activities)
- Help people to feel better if they have infections, fatigue or other symptoms.

Treatment Planning and Staging

The treatment plan for a person with CLL depends on the

- Stage of CLL (low risk, intermediate risk or high risk)
- Physical exam and lab test results
- Person's overall health
- Person's age (for some treatments).



CLL Staging. Many doctors use a system called “staging” to help plan treatment for people with CLL. Many doctors use the “Rai staging system,” which defines a person’s risk as follows:

Low-Risk CLL

- High lymphocyte count in the blood and the marrow.

Intermediate-Risk CLL

- High lymphocyte count in the blood and the marrow
- Enlarged (swollen) lymph nodes
or
- High lymphocyte count in the blood and the marrow
- Enlarged (swollen) lymph nodes, liver or spleen.

High-Risk CLL

- High lymphocyte count in the blood and the marrow
- Anemia (low red cell count)
or
- High lymphocyte count in the blood and the marrow
- A low platelet count.

Other lab test results may show signs of faster-growing disease (higher-risk CLL). This means the person needs closer follow-up with the doctor.

Blood Lymphocyte Doubling Time. A lymphocyte number that doubles in one year means that the person needs closer follow-up.

Beta 2-Microglobulin (B2M). B2M is a protein on CLL cells. A higher level of B2M may mean there are more CLL cells.

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Factors Under Study. Other factors called “CD38,” “IGVH” and “ZAP-70” may give doctors information about a person’s response to treatment. More study is needed to learn how these factors should affect treatment planning.



You can view, print or order the free LLS booklet *Chronic Lymphocytic Leukemia* to learn more about factors under study and other detailed information about CLL. Go to www.LLS.org/freematerials or contact the Information Resource Center for a copy.

Questions to Ask Your CLL Doctor

Talk with the doctor about how he or she plans to treat your CLL. This will help you to be actively involved in your care and to make decisions. This *Guide* includes questions to ask your doctor about treatment (see the back inside cover).

It may be helpful to write down the answers to your questions and review them later. You may want to bring a caregiver, a family member or a friend with you to your doctor appointments. That person can listen, take notes and offer support. Some people like to record information from the doctor and then listen to the recording at home.

People with CLL, and their families or caregivers, who are unsure about treatment may want to get a second opinion. For a list of Healthcare Question Guides about second opinions and other topics you can print, go to www.LLS.org/whattoask and click on “Healthcare Question Guides.” Or contact the Information Resource Center for copies.

Treatments for CLL

- Watch and Wait
- Single or combination drug therapy
- Supportive care
- Radiation therapy
- Splenectomy (surgery to remove the spleen)
- Treatment in a clinical trial
 - Drug therapy with new drugs or new drug combinations
 - High-dose chemotherapy and allogeneic stem cell transplantation

Watch and Wait

The “watch and wait” approach means that a doctor observes a person’s condition with physical exams and lab tests. The doctor does not treat the person with drugs or other therapies during the watch and wait period.

People with CLL may think that they should have treatment right away. But for people with low-risk (slow-growing) disease and no symptoms, it is best not to start treatment. With watch and wait, the person avoids the side effects of therapy until it is needed. Many studies have compared the watch and wait approach to early treatment for people with low-risk CLL. This is also an area of ongoing study in clinical trials. To date, no benefits of early treatment for people with low-risk CLL have been shown.

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A person with CLL in watch and wait needs follow-up visits with the doctor. At each office visit the doctor will check for any health changes. The results of exams and lab tests over time will help the doctor advise the person about

- When to start treatment
- The type of treatment to have.

Treatment will begin if a person develops symptoms or there are signs that the CLL is starting to grow. The doctor may advise a person to begin treatment if one or more of these signs develop:

- The number of CLL cells is much higher than it was
- The number of normal cells is much lower than it was
- The lymph nodes have become larger
- The spleen has become larger.

A person with any or all of these signs may start to feel too tired for normal daily activities.

Drug Therapy for CLL

People who have intermediate- and higher-risk (faster-growing) CLL are usually treated with combination chemotherapy and/or monoclonal antibodies.

Chemotherapy is treatment with drugs that kill or damage cancer cells. Some drugs are given by mouth. Other drugs are given through a vein by placing a small needle in the arm (called an IV). Two or more drugs are often used together. The FDA-approved drugs fludarabine (Fludara[®]), cyclophosphamide (Cytosan[®]), bendamustine (Treanda[®])

and other standard chemotherapies are used to treat people with CLL. Information about side effects of treatment for CLL starts on page 23.

Monoclonal antibody therapies for CLL are immune proteins that are made in the lab. They aim for a specific target on the surface of the CLL cells. The antibody attaches to the cell and then the cell dies. This type of therapy is given through a vein by placing a small needle in the arm (called an IV). Monoclonal antibody therapies do cause some side effects. In general, the side effects are milder than the side effects of chemotherapy (see pages 23 and 24).

Rituximab (Rituxan[®]) and alemtuzumab (Campath[®]) are two of the monoclonal antibody therapies used to treat people with CLL. Rituxan is being studied in clinical trials and is used in combination with chemotherapy. Other new monoclonal antibodies are being studied in clinical trials to treat people with CLL

Two or more drugs are often combined for CLL treatment. Fludara is often combined with other drugs to treat people with CLL who need drug therapy. For example:

- FC – Fludara, Cytosan
- FR – Fludara, Rituxan
- FCR – Fludara, Cytosan, Rituxan

Fludara combined with other drugs is being studied in clinical trials.

Treanda combined with other drugs is being studied in clinical trials to treat people with CLL. For example:

- Treanda, Rituxan
- Treanda, lenalidomide (Revlimid[®])

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Some Drugs Used to Treat CLL

Chemotherapy

Bendamustine (Treanda[®])
Chlorambucil (Leukeran[®])
Cladribine (Leustatin[®])
Cyclophosphamide (Cytosan[®])
Doxorubicin (Adriamycin[®])
Fludarabine (Fludara[®])
Prednisone
Vincristine (Oncovin[®])

Monoclonal Antibody Therapy

Alemtuzumab (Campath[®])
Lumiliximab*
Ofatumumab (Arzerra[®])*
Rituximab (Rituxan[®])*

Other Drugs

Flavopiridol [a kinase inhibitor]*
Lenalidomide (Revlimid[®]) [an immunomodulatory drug]*

**Under study in clinical trials*

Supportive Care

Supportive care is given to prevent or treat CLL symptoms and/or treatment side effects. Supportive care for CLL may include

Antibiotics to treat infections caused by bacteria or fungi. Infections are a risk for people with CLL. The disease and CLL treatment lower the number of infection-fighting white cells in the blood. People with repeat infections may also get injections (shots) of immunoglobulin (gamma globulin).

Blood transfusions or red cell growth factors to increase the red cell count. Anemia (low numbers of red cells) is a common side effect of chemotherapy. Examples of red cell growth factors are Aranesp[®] (darbepoetin alfa) and Procrit[®] (epoetin alfa).

Blood cell growth factors may help the patient tolerate the side effects of higher doses of chemotherapy. People with CLL should discuss the risks and benefits of treatment with blood cell growth factors with their doctors.

Growth factors to improve low white cell counts. CLL-related low blood counts are often corrected by CLL therapy. Sometimes the use of white cell growth factors can help people with CLL who have a long period of low white cell counts after treatment. Examples of white cell growth factors are Neupogen[®] or Neulasta[®] (also called “G-CSF”) and Leukine[®] (also called “GM-CSF”).

Other Therapies

Radiation Therapy. This treatment uses x-rays or other high-energy rays to kill cancer cells. Radiation therapy is sometimes used to treat a person with CLL who has an enlarged (swollen) lymph node, spleen or other organ that is blocking the function of a neighboring body part, such as the kidney or the throat.

Splenectomy. The spleen is an organ on the left side of the body, near the stomach. CLL cells can enlarge the spleen and cause discomfort in some people with CLL. Also, an enlarged spleen may lower the person’s blood cell counts to dangerous levels. An operation to remove the spleen is called a “splenectomy.” Splenectomy is helpful for some people with CLL if the spleen is very enlarged as a result of the disease. The operation may improve the person’s blood cell counts.

Treatment for Relapsed or Refractory CLL

“Relapsed CLL” is the term for CLL that responded to therapy but then stopped responding six or more months after therapy.

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“Refractory CLL” is the term used to describe CLL that either

- Does not result in a remission (but may be stable)
- Gets worse within six months of the last treatment.

People who are treated for relapsed or refractory CLL often have good quality years of remission after more treatment. Treatment options for people with relapsed or refractory CLL are generally the same as treatment for newly diagnosed people. But, some people who have refractory CLL may have

- A short time to CLL cell growth (disease progression) after the first treatment
- CLL cells with deletion of 17p (a chromosome change).

These people may have CLL that does not respond to standard drug therapy; they should speak to their doctors about treatment in a clinical trial.

Clinical Trials

Doctors are testing new drugs and new combinations of drugs to treat CLL. “Clinical trials” are used to study new drugs, new treatments or new uses for approved drugs or treatments. There are a growing number of CLL clinical trials for adults of all ages.

There are clinical trials for

- People with newly diagnosed CLL
- People with CLL who do not get a good response to treatment
- People with CLL who relapse after treatment
- People with CLL who continue treatment after remission (maintenance).

Some clinical trials test new ways to use drugs that are already approved. For example, changing the amount of the drug or giving the drug along with another type of treatment might be more effective. Ask your doctor if treatment in a clinical trial is right for you. You can also call the Information Resource Center for information about clinical trials or use TrialCheck[®], the free LLS-supported clinical trials service at www.LLS.org/clinicaltrials.

Some of the drug therapies under study in clinical trials are mentioned in the section that begins on page 17. Drugs under study in clinical trials are described in more detail on the free LLS booklet *Chronic Lymphocytic Leukemia*.



You can view, print or order the free LLS booklet *Understanding Clinical Trials for Blood Cancers* at www.LLS.org/freematerials or contact the Information Resource Center for a copy. You can also watch the free LLS Web video *My Clinical Trials Journey* at www.LLS.org/journeys.

Stem cell transplants are also under study in clinical trials. An “allogeneic stem cell transplant” is a type of stem cell transplant used to treat some diseases. This is a treatment to restore a person’s marrow. Allogeneic stem cell transplantation is under study for people with high-risk CLL. It may be a good treatment for some people younger than 55 years who are not doing well with other treatments. The person also needs to have a “matched” stem cell donor.

With an allogeneic stem cell transplant, stem cells from a donor are used. The donor can be a brother or sister. Or the donor can be another person with stem cells that “match” the stem cells of the transplant patient.

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First, the transplant patient is given high-dose chemotherapy and/or radiation therapy. Then stem cells from the donor are infused into the transplant patient's blood.

For people with CLL, an allogeneic transplant is done as part of a clinical trial. An allogeneic stem cell transplantation has a high risk of serious complications. Your doctor will explain the benefits and the risks if transplantation is suggested for you.

Doctors are working to make allogeneic stem cell transplants safer. A type of transplant called a “reduced-intensity transplant” is under study. A reduced-intensity transplant uses lower doses of chemotherapy than a standard allogeneic stem cell transplant. This treatment is also called a “nonmyeloablative” transplant. Older and sicker people may be helped by this treatment.



You can view, print or order the free LLS booklet *Blood and Marrow Stem Cell Transplantation* for more information. Go to www.LLS.org/freematerials or contact the Information Resource Center for a copy.

Side Effects of CLL Treatment

The term “side effect” is used to describe the ways that treatment affects healthy cells.

People react to treatments in different ways. Sometimes they have mild side effects. Other side effects may be serious and last a long time. Most side effects go away when treatment ends. In general, people have mild side effects with monoclonal antibody therapy.

Some possible side effects of CLL treatment include

Achy feeling	Low blood pressure
Diarrhea	Low platelet count
Constipation	Low red cell count (anemia)
Extreme tiredness	Low white cell count
Hair loss	Mouth sores
Infections	Upset stomach and vomiting

Talk to your doctor about the possible side effects and long-term effects of your treatment. You can also call the Information Resource Center.

You can view, print or order the free LLS booklet *Understanding Drug Therapy and Managing Side Effects* for more information. Go to www.LLS.org/freematerials or contact the Information Resource Center for a copy.



Treatment Response and Follow-Up

People with CLL have a range of responses after treatment. Talk to your doctor about the results of your treatment. Your doctor may use the following terms to talk about response to treatment:

Remission. No sign of disease; sometimes the terms “complete remission” (or complete response) or “partial remission” (or partial response) are used.

Complete Response (CR). No sign of disease for at least two months after the end of treatment; normal blood counts and hemoglobin greater than 11 g/dL without transfusions; no CLL signs or symptoms.

Partial Response (PR). At least a 50 percent reduction in the number of blood lymphocytes and in lymph node and spleen enlargement; one or

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more of the following must also be maintained for at least two months: platelets greater than 100,000/ μ l; hemoglobin greater than 11 g/dL; or a 50 percent improvement over pretreatment red cell or platelet counts without transfusions.

Stable Disease. This means the person's CLL is not growing, but the person does not have a complete or partial response.

Progressive Disease. The signs of progressive disease are at least one of the following:

- An increase of at least 50% in lymphocyte count or other signs of high-risk CLL
- An increase of at least 50% in liver or spleen size or a newly enlarged liver or spleen
- An increase of at least 50% in the combined size of at least two lymph nodes, in two exams in a row, done two weeks apart
- New appearance of enlarged lymph nodes.

Follow-Up Care. After CLL treatment, people need to see their doctors for physical exams and blood tests. Bone marrow tests or FISH may be needed from time to time. The doctor may recommend longer periods of time between follow-up visits if a person continues to be free of CLL signs or symptoms.

Minimal Residual Disease (MRD). Some people with CLL have a very low level of remaining CLL cells after treatment. The remaining CLL cells are called "minimal residual disease" (MRD). MRD cannot be detected by the usual blood and marrow tests. The tests to detect MRD in people with CLL are "four-color cell flow cytometry" and "polymerase chain reaction (PCR)." These tests may help the doctor to identify the need for more treatment.

Take Care of Yourself

- Keep all appointments with the doctor. People with CLL need medical follow-up after they have completed treatment. It is important to see if more therapy is needed.
- Discuss how you feel with the doctor at each visit.
- People with CLL may have more infections. Follow the doctor's advice for preventing infection.
- Eat healthy foods each day. It is okay to eat four or five smaller meals instead of three bigger ones.
- Contact the doctor about tiredness, fever or other symptoms.
- Do not smoke. People who smoke should get help to quit.
- Get enough rest and exercise. Talk with your doctor before starting an exercise program.
- Keep a healthcare file with copies of lab reports and treatment records.
- Have regular cancer screening. People with CLL have a risk for a second cancer, including melanoma, sarcoma, colorectal cancer, lung cancer, basal cell cancer, squamous cell skin cancer and myeloma.
- See the family doctor to keep up with other healthcare needs.
- Talk with family and friends about how you feel. When family and friends know about CLL and its treatment, they may worry less.
- Seek medical advice if your mood does not improve over time. For example, if you feel sad or depressed every day for a two-week period, seek help. Depression is an illness. It should be treated even when a person is being treated for CLL. Treatment for depression has benefits for people living with cancer.
- Remember that the outlook for people with CLL is improving. New treatments are on the horizon.

To order free LLS booklets, contact us at www.LLS.org or (800) 955-4572.

We're Here to Help

The Leukemia & Lymphoma Society (LLS) has chapters around the nation. LLS chapters offer support groups and can also arrange for a person with CLL to talk with another person who has CLL. To find the chapter in your area, call (800) 955-4572. Or visit the Web site at www.LLS.org.



You can view, print or order the free LLS booklets *Each New Day: Ideas for Coping with Blood Cancer* and *Financial Health Matters* for more information and support. Go to www.LLS.org/freematerials or contact the Information Resource Center to order copies. You can also watch the interactive LLS Web program *My Personal CLL Journey* at www.LLS.org/journeys.

Information for Veterans. Veterans with CLL who were exposed to Agent Orange while serving in Vietnam may be able to get help from the U.S. Department of Veterans Affairs. For more information call the Department of Veterans Affairs at (800) 827-1000 or visit www1.va.gov/AgentOrange.

Language Services. Members of your healthcare team want you to understand the information they are giving you. Let your doctor know if you want a professional healthcare interpreter who speaks your native language or uses sign language. Many times, this is a free service. Contact a patient advocate if you are not sure. For more information, contact the Information Resource Center (IRC) at (800) 955-4572. Language services are available for IRC calls.

Medical Terms

Antibiotics. Drugs that are used to treat infections caused by bacteria and fungi. Penicillin is one type of antibiotic.

Antibodies. Proteins made by plasma cells. Antibodies help to fight infection in the body.

Baseline testing. Tests that are used to get information before treatment to compare to information in the test results after treatment.

Beta 2-microglobulin. A cell protein that enters the blood. Measuring the amount of this cell protein can be one way to assess a person's type of CLL. A high level may mean the CLL is a faster-progressing type of CLL.

Bone marrow aspiration. A procedure to examine marrow cells. A liquid sample of cells is removed from the marrow and the cells are looked at under a microscope.

Bone marrow biopsy. A procedure to examine marrow cells. A very small amount of bone marrow filled with marrow cells is removed and the cells are looked at under a microscope.

Chemotherapy or drug therapy. Treatment with chemical agents to treat CLL and other diseases.

Chromosomes. Any of the 23 pairs of basic structures in human cells, which are made up of genes. Genes give the instructions that tell each cell what to do. One or more chromosomes may be changed in blood cancer cells.

Clinical trials. Careful studies done by doctors to test new drugs or treatments, or new uses for approved drugs or treatments. The goal of clinical trials for blood cancers is to improve treatment and quality of life and to find cures.

Join us for the latest information on CLL during our **free teleconferences**. Go to www.LLS.org or call **(800) 955-4572**.

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Medical Terms

Combination chemotherapy or drug therapy. The use of two or more drugs together to treat CLL and other diseases.

Diagnose. To identify a disease from a person's signs, symptoms and lab test results. A diagnosis is made by a doctor.

FDA. The short name for the United States (U.S.) Food and Drug Administration. Part of the FDA's job is to assure the safety, and security of drugs, medical devices, and the U.S. food supply.

FISH. The short name for a test called "fluorescence in situ hybridization." This is a test to measure the presence of a specific chromosome or gene in the cells. This test can be used to plan treatment and to measure the results of treatment.

G-CSF. The short name for granulocyte-colony stimulating factor, a natural substance that stimulates the growth of neutrophils (a type of white cell that fights infection). Chemotherapy kills cancer cells, but also decreases the number of neutrophils in the blood and marrow. G-CSF manufactured by genetic engineering (Neupogen and Neulasta) may be used to treat or prevent a low neutrophil count.

GM-CSF. The short name for granulocyte macrophage-colony stimulating factor, a natural substance that stimulates the growth of macrophages and other white cells that fight infection. Chemotherapy kills cancer cells, but also decreases the number of macrophages and other white cells in the blood and marrow. GM-CSF manufactured by genetic engineering (Leukine) is used to treat or prevent a low white cell count.

Hematologist. A doctor who treats blood cell diseases.

Medical Terms

Immune response. The body's reaction to foreign material such as a microbe, a vaccine, or donor cells used for a stem cell transplant.

Immune system. Cells and proteins in the body that defend it against infection.

Immunoglobulins. Proteins that fight infection.

Immunotherapy. The term for treatments that can boost the body's immune system.

Lymphocyte. A type of white cell that is part of the immune system and fights infection.

Marrow. The spongy material in the center of bones where blood cells are made.

Monoclonal antibody therapy. Immune proteins made in the laboratory. This type of therapy targets and kills specific cancer cells. They do not cause many of the side effects of chemotherapy.

Oncologist. A doctor who treats people who have cancer.

Pathologist. A doctor who identifies diseases by studying cells and tissues under a microscope.

PCR. The short name for “polymerase chain reaction,” a sensitive lab test that can measure cancer cell markers in the blood. It is used to detect cancer cells that cannot be detected by other tests, such as FISH.

Plasma. The liquid part of the blood.

Medical Terms

Platelet. A type of blood cell that helps prevent bleeding. Platelets cause plugs to form in the blood vessels at the site of an injury.

Red cell. A type of blood cell that carries oxygen to all parts of the body. In healthy people, red cells make up almost half of the blood.

Refractory CLL. CLL that has not responded to initial treatment. Refractory disease may be disease that is getting worse or staying the same (stable disease).

Relapsed CLL. CLL that responded to treatment but then returns.

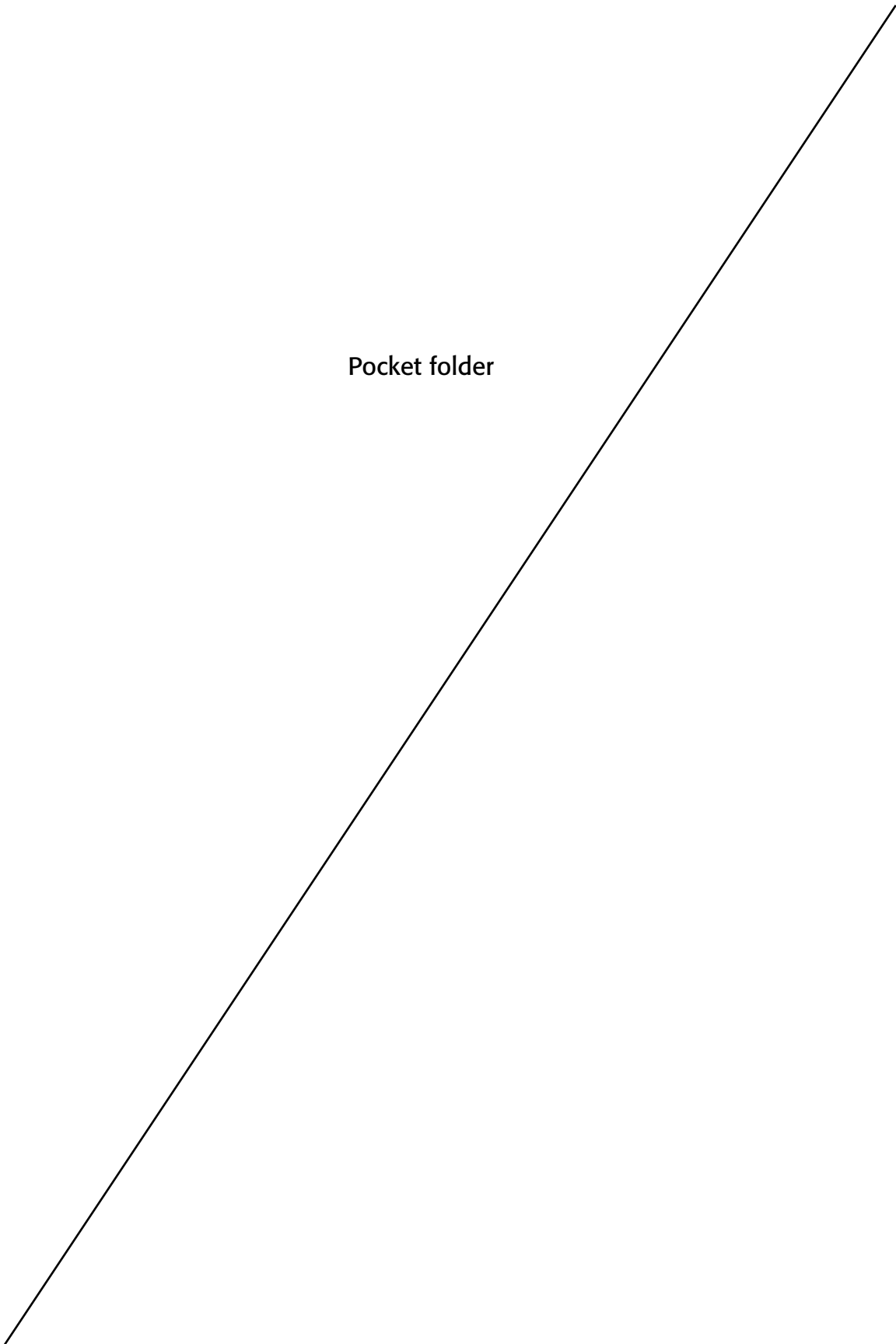
Remission. No sign of the disease and/or a period of time when the disease is not causing any health problems.

Richter transformation. A change to a faster-growing form of CLL that takes place for a small number of people with CLL that began as a slow-growing type.

Small lymphocytic lymphoma (SLL). A disease with symptoms and treatment that are much like CLL. SLL starts in a lymphocyte in a lymph node. CLL starts in a lymphocyte in the marrow.

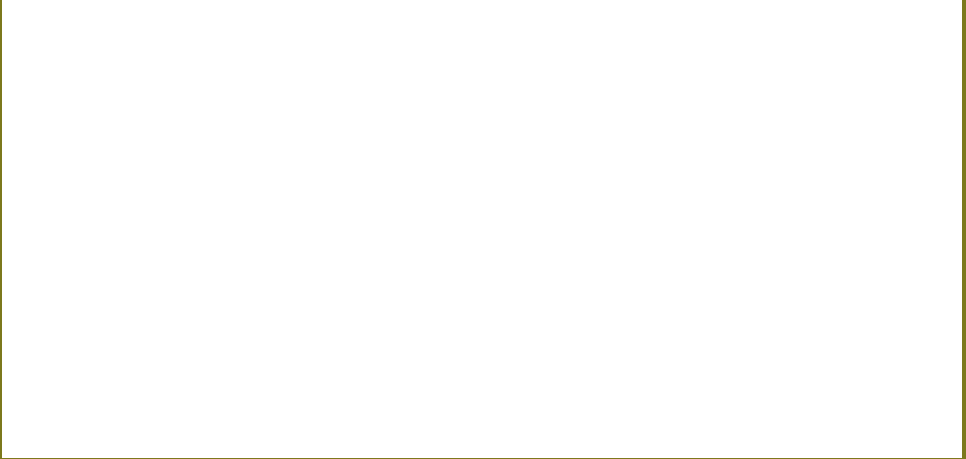
Stem cell. A type of cell found in marrow that makes red cells, white cells and platelets.

White cell. A type of blood or immune cell that helps the body fight infection.



Pocket folder

For more information, please contact:



or:

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Information Resource Center (IRC) 800.955.4572 (Language interpreters available upon request.)

www.LLS.org

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

LLS is a nonprofit organization that relies on the generosity of corporate, individual and foundation contributions to advance its mission.



**The Leukemia &
Lymphoma Society**[®]
Fighting Blood Cancers