



**The Leukemia &  
Lymphoma Society**<sup>®</sup>  
*Fighting Blood Cancers*

# CLL: A Guide for Patients and Caregivers

LEUKEMIA

LYMPHOMA

MYELOMA

CHRONIC LYMPHOCYTIC LEUKEMIA



# Introduction

In the U.S.

- In 2006, about 91,000 people were living with CLL
- In 2007, more than 15,000 people will learn they have CLL

Most people with chronic lymphocytic leukemia (CLL) are at least 50 years old. CLL is less common in people age 49 and younger.

This booklet is for patients with CLL, their families and caregivers. It will help them learn about CLL and how it is treated.

Progress in treating CLL gives patients more hope than ever before. There is no cure for CLL – but there are a number of treatments. Many people with CLL feel well and live for years with good health. Doctors are looking for new ways to treat CLL. The goal is to add more years of good health to the lives of people with CLL and to find a cure.

*This booklet about CLL is from the Leukemia & Lymphoma Society. It is for information only. The Society does not give medical advice or medical services.*

**1** **Questions? Contact an Information Specialist at The Leukemia & Lymphoma Society at [www.LLS.org](http://www.LLS.org) or (800) 955-4572.**

# Inside This Booklet

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**Medical Terms**

**We're Here to Help**

**S**ome words in the booklet may be new to you. Check “Medical Terms” at the back of this booklet.



**For more information about the disease and its treatment order The Leukemia & Lymphoma Society's free booklet, *Chronic Lymphocytic Leukemia*.**

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# Part 1 – Understanding Chronic Lymphocytic Leukemia

CLL is one of four types of leukemia. More people are living with CLL than any other type of leukemia.

It will help to know a little about the **blood**, **marrow** and **immune system** before you read more about CLL.

## Blood and Marrow

The **blood** is made up of blood cells and plasma.

**Plasma** is mostly water with vitamins, minerals, proteins, hormones and other natural chemicals.

Normal **stem cells** in the marrow form three main cell-types.

**Red cells** carry oxygen to all the tissues of the body, such as the heart, lungs and brain. When the number of red cells is below normal this is called **anemia**. People with anemia may feel tired, pale or short of breath.

**Platelets** prevent bleeding and form “plugs” that help stop bleeding after an injury. **Thrombocyte** is another word for platelet. When the number of platelets is below normal

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## Blood and Marrow (cont'd.)

this is called **thrombocytopenia**. People with a very low platelet count may bruise easily or have prolonged bleeding from cuts or injuries.

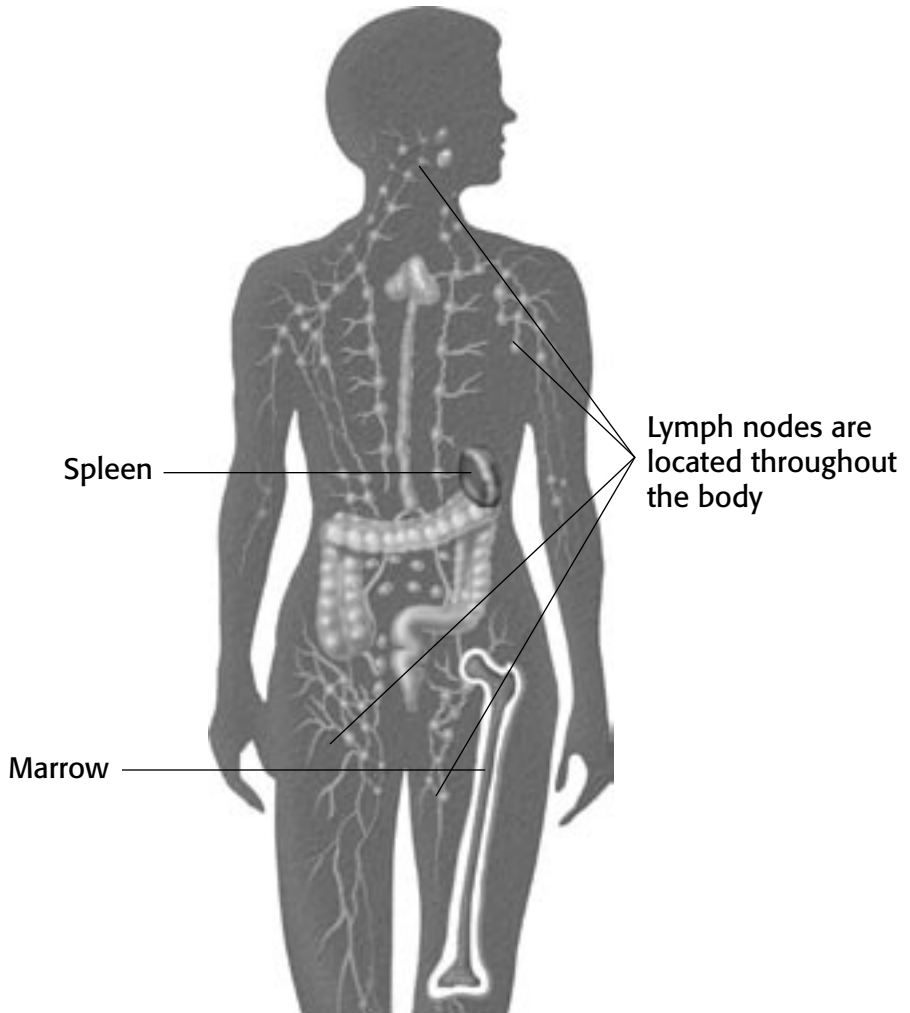
**White cells** fight infection in the body. There are two major types of white cells: germ-ingesting cells (**neutrophils** and **monocytes**) and **lymphocytes** (immune cells), which provide **immunity** to infection. When the number of neutrophils is below normal this is called **neutropenia**. People with a very low neutrophil count may develop repeated infections.

**Lymphocytes** are part of the body's **immune system**. The lymph nodes and the spleen are also part of the immune system. The normal immune system helps to protect the body from infection.

**Marrow** is the spongy center inside of bones where blood and immune cells are made. The marrow is really two organs in one: the blood cell-forming organ and the lymphocyte-forming organ, which is part of the immune system.

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## Some Parts of the Immune System



The normal immune system helps to protect the body from infection. The marrow, lymph nodes, lymphocytes and spleen are some of the parts of the immune system. There are about 600 lymph nodes throughout the body.

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CLL starts with a change to a single cell called a lymphocyte. Doctors are studying CLL to understand why this cell-change takes place.

The changed cell makes too many copies of itself. The CLL cells replace normal lymphocytes in the marrow and lymph nodes. The high number of CLL cells in the marrow may crowd out normal blood-forming cells. CLL cells do not fight infection like normal lymphocytes do.

In certain families, more than one blood relative has CLL. This is not common. Doctors are studying why some families have more than one relative with CLL.

## Signs and Symptoms

Patients may learn they have CLL after a blood test as part of a regular checkup. Sometimes, a person with CLL may notice enlarged lymph nodes in the neck, armpit or groin and go to the doctor.

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

CLL symptoms usually develop slowly. Some CLL patients may have no signs or symptoms in the early stages of CLL. These patients may have little or no change to their health for many years.

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Some people with CLL:

- May tire more easily (some patients may start to feel less energy when they have fewer healthy red blood cells and more CLL cells)
- May feel short of breath during normal activities (from low red cell count)
- May lose weight
- May have swollen lymph nodes or spleen (as the number of CLL cells grows, the cells can pile up in these areas)
- May have repeated infections of the skin or other parts of the body (from a very high number of CLL cells building up in the marrow).

The signs and symptoms of CLL are common to other illnesses.

## Blood and Bone Marrow Tests

Blood and marrow tests are used to **diagnose** CLL. There are different types of CLL.

These lab tests are also used to get information about the patient's type of CLL. They are also used to check a patient's response to treatment.

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**T**o **diagnose** means to identify a disease from the patient's signs and symptoms – and from test results. A diagnosis is made by a physician.

A patient's blood test may show that the lymphocyte count is increased. The blood test may also show low platelet counts and low red cell counts. A doctor will do other tests to find out if CLL is the cause for the high lymphocyte count.

**Flow cytometry** is used to find out if CLL is causing the high lymphocyte count. This test is also called **immunophenotyping**. Flow cytometry shows if the CLL is B-cell CLL or T-cell CLL. B-cell CLL is more common. Additional lab tests are done after a flow cytometry test shows the patient has CLL.

A **cytogenetic analysis** looks to see if there are changes to the chromosomes of the CLL cells. Some chromosome changes give doctors information about how to treat the patient's CLL.

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**FISH** (fluorescence in situ hybridization) is another test that is used to check for chromosome changes. After CLL treatment begins, this test can be used to see if treatment is working. This is done by measuring the number of cells with abnormal chromosomes that remain after treatment.

**E**very cell in the body has chromosomes that carry genes. Genes give the instructions that tell the cell what to do. Changes to the genes may mean that:

- Too many cells are made, or
- The cells live too long, or
- A type of cell does not work right. For example, CLL cells do not fight infection like normal lymphocytes do.

A **bone aspiration** and a **bone marrow biopsy** are used to look at CLL cells. These tests may be done in the doctor's office or in a hospital.

An **aspiration** helps doctors take a close look at the cells in the marrow. They can see the types of cells and changes to the cells. The **biopsy** gives information about how much CLL is in the marrow.

A **bone marrow aspiration** is done by removing a small amount of **fluid from the marrow**. A special needle is used. The patient gets medication first to numb the part of the body that will be used to get the fluid. It is usually the patient's hip bone. The cells are looked at under a microscope.

A **bone marrow biopsy** is done by removing a very small amount of **bone filled with marrow cells**. This is done with a special needle. Medication is given to numb the part of the body that will be used for the biopsy – usually the hip bone. The bone marrow sample is looked at under a microscope.

Bone marrow tests are not always done for CLL patients. Patients with more advanced CLL usually have a **baseline** bone marrow test.

**A** baseline test is used to get information before treatment to compare to test results after treatment. The results from the baseline bone marrow test are compared to a bone marrow test after treatment. This is one way to tell how the patient is doing after treatment.

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Doctors also may check the blood for **immunoglobulins** (gamma globulins). Immunoglobulins are proteins that help the body fight infection. CLL patients may not have enough of these proteins. With more advanced CLL, low levels of immunoglobulins may be a cause of repeated infections.



## Part 2 – Treatment

Each patient should talk to his or her doctor about CLL and treatment. A patient with CLL is usually treated by a doctor called a **hematologist** or an **oncologist**.

Some patients may want to get a second medical opinion. It is important to get treatment in a center where doctors are experienced in the care of patients with CLL.

There is no cure for CLL. Treatment goals are to:

- Slow the piling up of CLL cells
- Keep patients feeling well enough to carry on their day-to-day activities
- Protect patients from infection

There are different types of CLL. Some patients' disease progresses slowly. Patients with CLL that is:

- Not growing, or
- Slow-growing

and who have no symptoms may not need treatment for a long time after diagnosis. This is sometimes called “watch and wait” or “watchful waiting.”

For other patients the disease may progress more quickly. Most patients require treatment at the time of diagnosis or soon after.

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## Watch and Wait

**W**atch and wait is when a doctor closely watches a patient's condition without giving any treatment. Patients may think they should have treatment. But for patients with slow-growing disease and no symptoms it is usually best not to start treatment right away. This allows the patient to avoid side effects until treatment is needed.

CLL patients in **watch and wait** need 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 talk to the patient about:

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

A doctor may advise a patient 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 patient with any or all of these signs may start to feel too tired for normal daily activities.

Many doctors use **staging** (stages 0-4) to help plan a CLL patient's treatment.

To “stage” a patient's CLL a doctor considers:

- The patient's number of CLL cells
- If the patient's lymph nodes, spleen or liver is enlarged
- If the patient is anemic (red cells less than normal)
- If the patient has a very low platelet count.

A high level of beta 2-microglobulin may be a sign of faster-growing disease. Beta 2-microglobulin is a cell protein that can be measured in the blood.

Other changes in the patient's CLL cells may also help doctors decide when and what type of treatment is needed.

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## Drug Treatment



**More information about CLL treatment is in the Society's free booklet, *Chronic Lymphocytic Leukemia*.**

Patients who have faster-progressing disease (higher stage number) are usually treated with **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 may be used together.

**Monoclonal antibodies** are immune proteins that are made in the lab. They work by targeting and killing cancer cells. They do not result in many of the side effects caused by chemotherapy.

## Some Drugs Used to Treat CLL

Drug	Brand Name
Chlorambucil	Leukeran®
Cladribine	Leustatin®
Cyclophosphamide	Cytoxan®
Doxorubicin	Adriamycin®
Fludarabine	Fludara®
Prednisone	Deltasone®
Vincristine	Oncovin®
Alemtuzumab	Campath®
Rituximab	Rituxan®

Fludarabine or cladribine is the first drug treatment for some patients. Two monoclonal antibodies are used to treat some CLL patients. These are Rituxan® and Campath®.

Rituxan® is used with chemotherapy. Fludarabine, cyclophosphamide and Rituxan® are examples of drugs that may be given together. Campath® is usually used for CLL patients who have not responded to other drugs.

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## Allogeneic Stem Cell Transplantation

Allogeneic stem cell transplantation is used to treat some CLL patients. This is a treatment to restore a patient's marrow. First, the patient is given high-dose chemotherapy and/or radiation therapy. Then stem cells are taken from a donor and given to the patient. The donor can be a brother or sister. Or the donor can be another person with stem cells that “match” the patient's. This treatment is done in the hospital.

**An allogeneic stem cell transplant is a high-risk procedure.** For this reason, it is not a good treatment for all CLL patients. The treatment is not used for older patients or patients with slow-growing CLL. A patient who might be treated with allogeneic stem cell transplantation usually:

- Has a fast-growing form of CLL
- Is younger than age 55
- Has a relative who is a “match” to donate stem cells.

The decision to have a stem cell transplant also depends on the other good treatment choices for the patient.

**D**octors are working to make stem cell transplants safer. In the future, more CLL patients may have this treatment.

A type of transplant called a mini-transplant is under study. A mini-transplant uses lower doses of chemotherapy in combination with an allogeneic stem cell transplant. This treatment is also called a nonmyeloablative transplant. Older and sicker patients may be able to be helped by this treatment. To learn more about stem cell transplants, speak to your doctor. You can also call the Society.



**The Society's free booklet, *Blood and Marrow Stem Cell Transplantation*, has more information on this topic.**

## **Other Treatments**

**Radiation therapy** uses X-rays or other high-energy rays to kill cancer cells. Radiation therapy is not a common treatment for CLL. It may be used if a CLL patient has an enlarged lymph node, spleen or other organ that is blocking a normal body function.

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**Splenectomy** is an operation used for a very small number of CLL patients. The spleen is an organ on the left side of the body, near the stomach. Its job is to clean worn out cells from the blood. If the spleen gets filled with too many CLL cells it may cause discomfort or pressure. Also, a large spleen may lower blood cell counts to dangerous levels. Then it might be removed by surgery. Only some patients benefit from removal of the spleen. Removing the spleen can cause complications. For this reason, it would only be done if other treatments were not an option.

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

## Side Effects

CLL patients should talk with the doctor about **side effects** before they begin treatment.

**T**he main effect of treatment for CLL is to kill CLL cells. The term side effect is used to describe how treatment affects healthy cells.

Patients react to CLL treatment in different ways. Sometimes patients have no side effects. Sometimes side effects are mild and last only a short time. Other side effects may be serious and last a long time. Most side effects go away when patients complete treatment.

Some side effects of CLL treatment:

- Low red cell count (anemia)
- Extreme tiredness
- Infection
- Upset stomach
- Hair loss.



**For more information about medications and side effects of treatment, order the Society's free booklet, *Understanding Drug Therapy and Managing Side Effects*.**

To order free booklets, contact **The Leukemia & Lymphoma Society** at [www.LLS.org](http://www.LLS.org) or **(800) 955-4572**.

## Follow-up

Medical follow-up is important for all CLL patients. Follow-up helps the doctor identify if there is a need for more treatment.

Patients need to see their doctors for exams and blood tests. Bone marrow tests may be needed from time to time. Patients may need other tests – including cell flow analysis, FISH or PCR. PCR (polymerase chain reaction) is a very sensitive test that may be used to measure any remaining CLL cells that cannot be detected by FISH. The doctor may recommend longer periods of time between follow-up visits if a patient continues to be disease free.

Patients should talk to the doctor about how often to have follow-up visits. They can ask what tests they will need – and find out how often to have the tests. Patients should talk with their health care providers about any long-term effects of treatment.



**Cancer-related fatigue can be a long-term effect of treatment for some patients. The Society's free fact sheet, *Fatigue*, has more information on this topic.**

## Clinical Trials

New cancer treatments are studied in clinical trials. The goal is to help more patients have good responses to treatment or be cured.

Cancer clinical trials use volunteers to test new and better ways to:

- Diagnose and treat CLL and other cancers
- Prevent or relieve side effects
- Prevent a return of disease
- Improve quality of life.

Doctors are testing new drugs and new ways to use approved drugs to treat CLL – for example, changing the dose or giving the drug along with another type of treatment. Doctors are also studying new lab tests that will help them identify when to begin treatment and which treatments to use.



**The Society's free booklet, *Understanding Clinical Trials for Blood Cancers*, explains clinical trials. The free booklet, *Chronic Lymphocytic Leukemia*, has more information about clinical trials for CLL.**

To order free booklets, contact **The Leukemia & Lymphoma Society** at [www.LLS.org](http://www.LLS.org) or **(800) 955-4572**.

**A**sks your doctor if treatment in a clinical trial is a choice for you. Or call the Society's Information Resource Center at (800) 955-4572 for more information about clinical trials.

## **Coping with CLL**

CLL patients should talk with their family and friends about how they feel. They can share what they know about the disease. Family, friends and caregivers can often help patients cope with what lies ahead. Also, patients with CLL may get to know one another. These friendships help too.

Patients should talk with their doctors about how the doctor plans to treat the disease. This will help them to be involved and to make decisions.

**It may be helpful to write down questions to ask the doctor.** Patients or caregivers can write down your doctor's answers and review them later.

**Patients may want to have a family member or friend come to the doctor with them.** This person can listen, take notes and offer support. Some patients record information and listen to it at home.

## **Some questions to ask the doctor:**

- What do the blood tests show? How do the results compare to “normal”?
- When will these tests need to be repeated?
- Will you send copies of your notes and my test results to my family doctor?
- What types of things should I call you about? What types of things should I call my family doctor about?
- When do you think I will need treatment?
- What kind of treatment do you think I will need?
- How much experience do you have treating patients with CLL?
- What side effects should be expected from treatment?
- What can I do to help deal with side effects?
- What can I do to reduce the risk of infection?
- Will the treatment be paid for by my health plan (or Medicare)?
- Should I be treated in a cancer clinical trial?
- How often and how long will I need treatment/ follow-up visits?
- What type of follow-up tests will be needed?
- Will I need to change our daily routine?
- How do I contact you after normal business hours?

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## **CLL patients can help take care of themselves by:**

- Keeping all appointments with the doctor.
- Following the doctor's advice for preventing infection.
- Eating healthy foods each day. It is okay to eat four or five smaller meals instead of three bigger ones.
- Contacting the doctor about tiredness or other symptoms.
- Not smoking. Patients who smoke should get help to quit.
- Getting enough rest and exercise. Talk with your doctor before starting an exercise program.
- Keeping a health care file with copies of lab reports and treatment records.
- Seeing the family doctor to keep up with other health care needs.

Making treatment choices can cause stress. The time and money spent for medical care may be a burden. Patients and caregivers can ask their health care team for help. The team can give emotional support. They can refer patients to other sources of help.

It is important to seek medical advice if a patient's mood does not improve over time – for example, if a person is feeling depressed every day for a two-week period.

Depression is an illness. It can be treated even when a person is being treated for CLL. Treatment for depression has benefits for people living with cancer.

The outlook for CLL patients continues to improve and new treatments are on the horizon.



**The Society's free booklets, *Each New Day: Ideas for Coping with Leukemia, Lymphoma and Myeloma* and *Coping: Support for People Living with Leukemia, Lymphoma or Myeloma*, have more information on this topic.**

**The Leukemia & Lymphoma Society has free materials, including**

*Choosing and Communicating with a Cancer Specialist* fact sheet

*Choosing a Treatment Facility* fact sheet

*Financial Health Matters*

*Immunotherapy* fact sheet

*Long-Term and Late Effects of Treatment for Blood Cancers* fact sheet

*Understanding Blood Counts* fact sheet

*Understanding Leukemia*

*Vaccine Therapy Facts*

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# Call Our Information Resource Center

The Society's Information Resource Center (IRC) 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 (800.955.4572) Monday through Friday, 9 am to 6 pm (ET); via email ([infocenter@LLS.org](mailto:infocenter@LLS.org)); or chat online at [www.LLS.org](http://www.LLS.org) (click on "Live Help").

Call 800.955.4572 for a complete directory of our patient services programs.



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LEUKEMIA

LYMPHOMA

MYELOMA

# Medical Terms

## **Antibiotics**

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

## **Beta 2-microglobulin**

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

## **FISH**

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

## **Hematologist**

A doctor who treats blood cell diseases.

## **Immune System**

Cells and proteins that defend the body against infection. Lymphocytes, lymph nodes and the spleen are some parts of the immune system.

## **Immunoglobulin (Gamma globulin)**

A protein found in the blood. Injections of gamma globulin may be given to patients to prevent or treat infection.

## **Immunotherapy**

The term for treatments that can boost the body's immune system. Immunotherapies are being studied for leukemia treatment. One example is vaccine therapy. This type of vaccine would not prevent leukemia, but would help the immune system's attack against leukemia cells.

## **Monoclonal Antibody**

A type of drug therapy that targets and kills cancer cells. Monoclonal antibodies are immune proteins made in the laboratory. They do not cause many of the side effects of chemotherapy.

## **Oncologist**

A doctor who treats patients with cancer.

## **PCR**

The short name for a lab test called "polymerase chain reaction," a very sensitive test that can measure the presence of a blood cancer cell marker in the blood. It is used to detect remaining blood cancer cells that are below the detection of cytogenetic methods (e.g., FISH).

**Refractory disease**

Disease that does not respond to therapy.

**Relapse or recurrence**

A return of disease after it has been successfully treated.

**Remission**

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

**Richter transformation**

A change to a faster-growing form of CLL that takes place for a small number of patients 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.

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## We're Here to Help

The Leukemia & Lymphoma Society has chapters around the nation.

**T**he Society's chapters offer support groups and also can arrange for a CLL patient to talk with another person who has CLL. To find the Society's chapter in your area, call (800) 955-4572. Or go to the Society's Web site at [www.LLS.org](http://www.LLS.org).



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For more information, please contact:



or:

Home Office

1311 Mamaroneck Avenue

White Plains, NY

Information Resource Center (IRC) 800.955.4572

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

*Our Mission: Cure leukemia, lymphoma,*

*Hodgkin's disease and myeloma, and improve the*

*quality of life of patients and their families.*

The Society is a nonprofit organization that relies on the generosity of corporate and individual contributions to advance its mission.



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