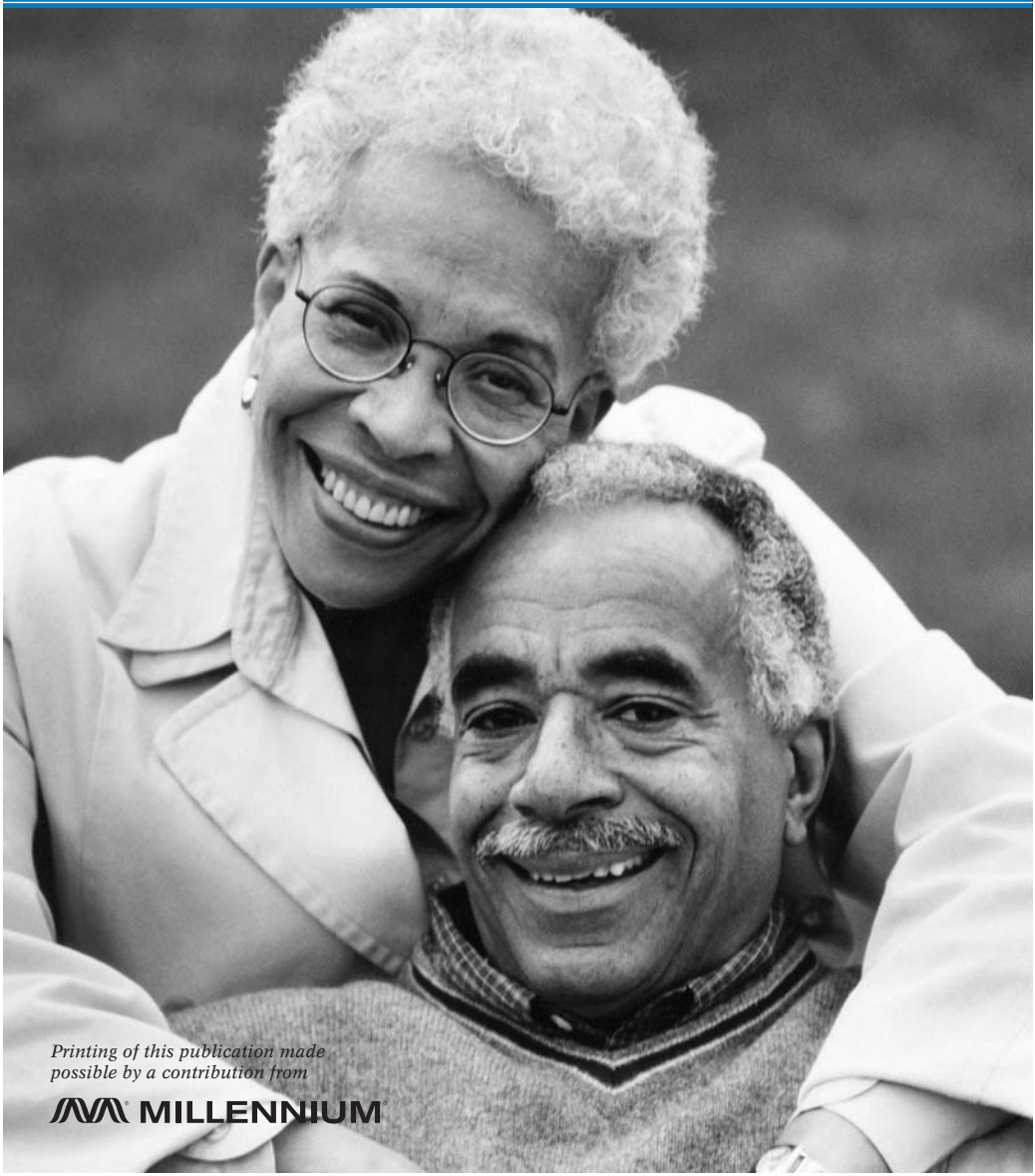
The Leukemia & Lymphoma Society®

*Fighting Blood Cancers*

# Myeloma: A Guide for Patients and Caregivers

LEUKEMIA | LYMPHOMA | MYELOMA



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MILLENNIUM

**Myeloma is a type of cancer.**
There is no cure for myeloma. Still, this is a hopeful time for myeloma patients. There are more treatments today than in the past. And new treatments are being studied.

About 16,500 Americans will be diagnosed with myeloma this year.

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About 58,000 people in the U.S. are living with myeloma.

**This booklet is for myeloma patients and their families.**
It will help you learn about myeloma and how it is treated.

**Part 1 answers the questions:**
- What is myeloma?
- Who gets myeloma?
- How does the doctor find myeloma?

**Part 2 answers the questions:**
- What are the treatments for myeloma?
- How do I get more information?

Some words in the booklet may be new to you. Check Medical Terms at the back of this booklet. Or call The Leukemia & Lymphoma Society at (800) 955-4572.

# The Society Has Free Booklets

Patients and their families may want to learn more about myeloma after reading this booklet.

The Society's booklet **Myeloma** has more details about the disease and its treatment.

**Blood and Marrow Stem Cell Transplantation** is about stem cell transplantation.

**Each New Day** is about support for people with myeloma and other blood cancers.

**Financial Health Matters** is about financial aid, insurance and ways to manage money.

**Understanding Clinical Trials for Blood Cancers** is about research for new treatments for myeloma and other blood cancers.

**Understanding Drug Therapy and Managing Side Effects** is about cancer drugs and side effects.

The Society's **fact sheets** may help you to understand and plan your health care:

- **Understanding Blood Counts**
- **Choosing and Communicating With a Cancer Specialist**
- **Choosing a Treatment Facility**

# Part 1 – Understanding Myeloma

**Myeloma is a cancer of plasma cells.** Plasma cells are part of the body's **immune system**. The job of the immune system is to protect the body from infections.

**Myeloma starts in marrow. Marrow** is the spongy tissue in the center of bones.

**Doctors do not know why some people get myeloma and others do not.** There is no way to prevent it. You cannot catch myeloma from someone who has it.

**Most people with myeloma are age 50 and older.** Americans of African descent get myeloma about twice as often as Americans of European descent. People of Asian and Hispanic descent have lower rates of myeloma.

# About Marrow, Blood and Blood Cells

**Marrow** is the spongy center inside bones.

**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.

**The blood is also made up of plasma.** Plasma is mostly water. It also has some vitamins, minerals, proteins, hormones and other natural chemicals.

**Platelets** prevent bleeding and form plugs that help stop bleeding after an injury.

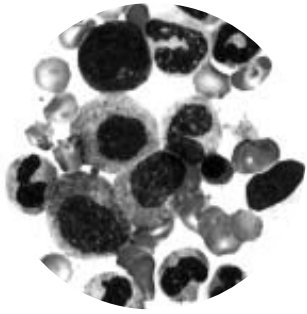
**Red cells** carry oxygen around the body. When the number of red cells is below normal it is called **anemia.** Anemia can make you tired, pale or short of breath.

**White cells** fight infection in the body. **Lymphocytes** are one type of white cell. Lymphocytes can be B lymphocytes, T lymphocytes or Natural Killer cells. All of these cell types help fight infection.

**Plasma cells** are part of the body's **immune system.** Plasma cells make **antibodies.** Antibodies help fight infection.

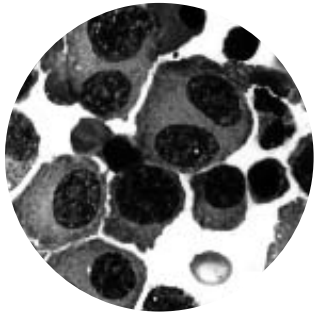
Myeloma starts with a change to a single cell called a B lymphocyte.

**Myeloma is a cancer of plasma cells.** It is normal for some B lymphocytes to become **plasma cells.** In myeloma, the change in the B lymphocyte causes it to become a myeloma cell instead of a normal plasma cell.



Normal Cells

**Myeloma cells** cannot help the body fight infection. As the myeloma cells grow in the marrow they crowd out the normal plasma cells. They also crowd out normal white cells and red cells.



Myeloma Cells



**Questions?** Contact an **Information Specialist** at **The Leukemia & Lymphoma Society** at **www.LLS.org** or **800-955-4572**.

# Some Types of Myeloma

**The most common form of myeloma is found in the marrow of many bones in the body.** It is sometimes called **multiple myeloma.**

Some people have a **single clump of myeloma cells** outside the marrow. This is called an **extramedullary plasmacytoma.**

**Extramedullary** means that the mass of myeloma cells is **outside the marrow.**

**Plasmacytomas** can form in the skin, muscle, lungs or almost any other part of the body.

Rarely, people with myeloma have **solitary myeloma**. This means they have **one area** of myeloma.

Some cases of myeloma **take a long time to progress.** These cases are called **smoldering** or **indolent myeloma.**

Sometimes patients with **smoldering** or **indolent myeloma** are not treated right away. In most cases treatment is needed at some point.

**The doctor does tests to find out what type of myeloma a patient has.**

**In the early stage of the disease some patients have no symptoms.**

Patients may find out about their myeloma after a routine check-up.

More often patients may have bone pain, bone fractures with no known cause, or low red cell counts.

Doctors do special tests to look for signs of myeloma.

- Bone marrow biopsy
- Lab tests
  - blood tests
  - urine tests
- Imaging tests
  - X-rays (skeletal surveys)
  - CT scans
  - MRIs
  - PET scans

**A bone marrow biopsy is done to see if myeloma cells are in the patient's marrow.** This test may be done in the doctor's office or in a hospital. The marrow is usually taken from the hip bone. First, the patient gets an injection to numb the skin. Then a needle is used to go into the bone and remove a small amount of marrow. The marrow is looked at under a microscope to see if there are myeloma cells.

Lab tests are done to see if a protein called **M protein** or **M spike** is in the patient's plasma and urine. M protein (**M** is for **monoclonal**) is an abnormal protein made by myeloma cells. The amount of M protein is one way to estimate the stage of the myeloma.

Another protein called **light chains** can be found in the myeloma patient's urine. This protein is also called **Bence Jones protein.**

**Other tests to find myeloma are called imaging tests.** X-rays of areas of bone pain, x-rays of skull, spine and ribs (skeletal survey), CT scans, MRIs and PET scans are types of **imaging tests.** X-rays and CT scans are used to see if there are any holes, breaks or thinning of the bones. MRIs and PET scans look for changes to marrow and pockets of myeloma cells.

**Lab and imaging tests are done to measure the extent of myeloma.** These are listed on page 11.

**Myeloma patients may have problems from their disease.**

- **Infections**
  Myeloma patients may have more infections. This is because myeloma cells do not make **antibodies** to fight infection. Patients should follow the doctor's advice about how to reduce their risk. The doctor may give **antibiotics** to treat infections.

- **Bone pain**
  Myeloma may cause bone pain. Drugs called **bisphosphonates** (Aredia® or Zometa®) may help. Bisphosphonates work by blocking the myeloma cells from making the bones weak.

- **Kidney problems**
  Myeloma patients have a protein called **light chains** or **Bence Jones protein**. Myeloma patients may also have high levels of calcium in their blood. Each of these can damage the kidneys. The doctor will check the patient's kidneys.

- **Acute myelogenous leukemia (AML)**
  A small number of patients develop another disease called AML.

# Part 2 – Treatment

**There are more treatments today than a few years ago.**

**The goals of treatment are:**

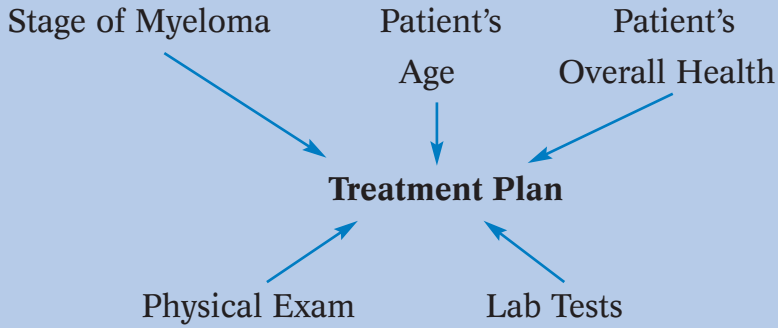
- To slow the growth of the myeloma cells.
- To help patients who have bone pain, fatigue or other problems from their disease to feel better.

**The treatment a patient gets depends on:**

- The type and stage of myeloma.
- The patient's age.
- The patient's overall health.

**Many doctors use a staging system (I, II or III) to help plan myeloma treatment.**

## How Is a Treatment Plan Made?



**Lab and imaging tests are done to stage (measure the extent of) myeloma.**

- Blood counts of red or white cells. These may be lower than normal with myeloma.
- The amount of M protein found in blood and urine. The protein is made by the myeloma cells.
- Blood calcium levels. These may be higher than normal with myeloma.
- Blood **beta 2-microglobulin** levels. These may be higher than normal with myeloma. Beta 2-microglobulin is a protein found on the surface of plasma cells and some other cells.
- **Albumin in the blood** (may be lower than normal).
- **How many parts of the bones** the myeloma has affected.

Doctors also use lab tests such as a **FISH** test to see if there are **changes to chromosomes** of the myeloma cells.

Every cell in the body has chromosomes that carry genes. Genes give instructions that tell each cell what to do.

**Treatments for myeloma include:**

- **Treatment with drugs that kill or damage cancer cells.** Some chemotherapy or other drugs are given by mouth. Other drugs are given through a vein. A small needle is placed in the arm (called an IV). Chemotherapy can result in a good period of remission for some patients.

- **A combination of treatments.** Most patients get two or more drugs that are often used together. Some combinations are melphalan and prednisone with thalidomide (MPT) or with Revlimid® (MPR) or with Velcade® (MPV). Patients may be treated with other combinations such as thalidomide and dexamethasone. Several other drug combinations are also used.

- **Certain drugs that can increase red cells.** Erythropoietin (Procrit®) and darbepoetin-alpha (Aranesp®) are drugs that may help with anemia. They can decrease the need for blood transfusions.

- **Radiation therapy (treatment with x-rays or other high-energy rays)**. It may be used to treat patients with solitary myeloma.

  Radiation therapy may also be used to treat a clump of myeloma cells outside the marrow. This is called a **plasmacytoma**.

## Some Myeloma Drugs

| Generic Name | Brand Name |
|---|---|
| Melphalan | Alkeran® |
| Vincristine | Oncovin® |
| Doxorubicin | Adriamycin® |
| Carmustine | BiCNU®, BCNU® |
| Cyclophosphamide | Cytoxan® |
| Bortezomib | Velcade® |
| Thalidomide | Thalomid® |
| Arsenic trioxide | Trisenox® |
| Interferon alfa | Roferon® A, Intron® A |
| Dexamethasone | Decadron® |
| Prednisone | (Many brands) |
| Pamidronate | Aredia® |
| Zoledronic acid | Zometa® |
| Lenalidomide | Revlimid® |

**Doctors are testing new drugs and new combinations of drugs to treat myeloma.** Doctors are also testing new ways to use drugs that are already approved. For example, changing the amount or giving the drug along with another type of treatment might be better.

# Some Drugs Used in Treatment and Studies

**Bortezomib** (Velcade®) is given by injection. It is used for patients who have tried at least one other treatment that has not helped. **Velcade®** is also being used in clinical trials (research studies) as a first-line treatment either alone or in combination with other drugs such as thalidomide.

**Thalidomide** (Thalomid®) is given by mouth. Thalidomide is used with dexamethasone to treat newly diagnosed myeloma patients. It is also being studied together with other drugs.

**Lenalidomide** (Revlimid®) is a drug like thalidomide. It may be safer and work better for myeloma patients. Revlimid® is used with dexamethasone to treat myeloma patients who have already had at least one other type of treatment.

**Arsenic trioxide** (Trisenox®) is given by injection. It is being tested in clinical trials for relapsed patients or patients who have not responded to other treatment. It is being tested with vitamin C and melphalan. This is called **MAC therapy.**

# Clinical Trials

**New treatments are studied in clinical trials.**
To learn more about clinical trials ask your doctor if a clinical trial might help you. You can also call the Society for information about clinical trials.

**The goals of new drug studies are to add years of good health to myeloma patients and to find a cure.**

## Some Clinical Trials for Myeloma Treatments

- Thalidomide/Velcade®
- Velcade®/drug therapy (doxorubicin and steroids)
- Arsenic trioxide (Trisenox®)/Revlimid®
- Stem cell transplantation
- Thalidomide or Revlimid® as maintenance therapy after stem cell transplant or chemotherapy
- Vaccines to treat (not prevent) myeloma



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## Radiation Therapy and Stem Cell Transplantation

- **High-dose drug or radiation therapy followed by stem cell transplant is another treatment.** The goal of high-dose drug therapy or radiation is to kill all myeloma cells. These treatments can also kill normal cells in the marrow.

  A **stem cell transplant** is a treatment to help the patient's marrow make new blood cells after high-dose drug or radiation therapy. Stem cell transplant is a choice for some patients. This treatment is done in the hospital.

**Having a stem cell transplant depends on a number of things, such as:**

- What other good treatment choices the patient has.
- The patient's physical ability to handle a stem cell transplant.

**There are two main types of transplant.**
When a patient's own stem cells are used, it is called an **autologous stem cell transplant**. This is the most common type for myeloma patients.

With a stem cell transplant, stem cells are collected before drug therapy. They are injected into the patient's blood after drug therapy. The transplanted stem cells go to the marrow and help start a new supply of red cells and white cells.

High-dose chemotherapy plus autologous stem cell transplant is not a cure. It does give patients longer disease-free periods than standard-dose chemotherapy without a stem cell transplant.

**Another type of stem cell transplant is called an allogeneic stem cell transplant.** With this type, 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 patient's.

**Allogeneic stem cell transplants are used less often to treat myeloma than autologous stem cell transplants.** Allogeneic stem cell transplants are being studied in myeloma patients younger than age 55 who are not doing well with other treatments.

**An allogeneic stem cell transplant is a high-risk procedure.** For this reason, it is not a good treatment for all myeloma patients. An allogeneic stem cell transplant may be a good treatment for myeloma patients who are not doing well with other treatments if the expected benefits of a stem cell transplant exceed the risks. For myeloma patients allogeneic transplants are usually done as part of a clinical trial (research study).

Doctors are working to make stem cell transplants safer. In the future, more myeloma patients may be able to have stem cell transplants.

# Stem Cell Transplants Under Study

**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.

**Cord blood stem cell transplants** (stem cells are obtained from **umbilical cord** blood. One cord blood unit provides enough stem cells for a child or small adult. Clinical trials are ongoing using multiple cord blood units from more than one donor to make this stem cell resource available for average-size adults).

**Tandem transplants are also under study**. A **tandem stem cell transplant** is the name for a treatment with 2 transplants. A patient who has a tandem stem cell transplant has one autologous transplant and then a second autologous transplant within 6 months. The goal of tandem transplants is to eliminate the disease completely.

**Another type of tandem transplant** is under study. The first transplant is an autologous stem cell transplant. The second one is a mini-allogeneic stem cell transplant.

To learn more about stem cell transplants, speak to your doctor. You can also call the Society.

## Side Effects

**Myeloma patients should talk with their doctors about side effects before they begin any type of treatment.**

The **main effect** of treatment for myeloma is to kill myeloma cells. The term side effect is used to describe how treatments affect healthy cells.

**Patients react to treatments in different ways.** Sometimes there are very mild side effects. Other side effects may be serious and last a long time.

Some side effects of treatments

- Upset stomach and vomiting
- Mouth sores
- Constipation
- Extreme tiredness
- Infections
- Low red cell count (anemia)
- Low white cell count
- Low platelet count
- Achy feeling
- Numb feeling in arms, hands, legs or feet

## Tests to See if Treatment Is Working

**Your doctor does tests to see if treatment is working.** Tests are done throughout treatment. The test results help the doctor to decide if changes to treatment are needed.

**Blood** and **urine tests** are done to check blood cell counts, kidney function and growth of myeloma cells.

A **bone marrow biopsy** is used to look at the amount and pattern of myeloma cells in the marrow.

A bone marrow biopsy is also used to do a **cytogenetic analysis.**

A cytogenetic analysis looks to see if there are **changes to chromosomes** of the myeloma cells.

Each cell has **chromosomes that carry genes**. Genes give the instructions that tell each cell what to do.

There may be too many, too few or broken chromosomes.

**Imaging tests (x-rays, CT scans, MRIs and PET scans) are used to look at the bones and marrow.** X-rays and CT scans are used to see if there are any holes, breaks or thinning of the bones. MRIs and PET scans look for changes to marrow and pockets of myeloma cells.

# Responses to Treatment

The doctor may use these terms to talk about a patient's response to treatment.

**Remission**
No sign of disease. Sometimes the terms **complete remission** (response) or **partial remission** (response) are used.

**Complete remission or response**
No sign of M protein in blood and urine. Normal percent of plasma cells or no sign of myeloma cells in marrow.

**Partial remission or response**
More than a 50% decrease in M protein in the blood.

**Complete molecular remission or response**
No sign of myeloma cells in the marrow using very sensitive tests.

**Minimal response**
Less than a 50% decrease in M protein in the blood.

**Progressive disease**
More than a 25% increase in M protein in the blood, new areas of bone damage or a new clump of myeloma cells (plasmacytoma).

**Myeloma specialists know about new tests and treatments for your disease.**

## Choosing and Talking to a Specialist

Choose a doctor who specializes in treating myeloma. Or have your local cancer specialist work with a myeloma specialist.

**Ways to Find a Myeloma Specialist**

- Your primary care doctor
- Your community cancer center
- Local medical society
- Physician referral services
- Health plan referral services
- The Leukemia & Lymphoma Society
- Family and friends

# What Should I Ask the Doctor?

**Talk with the doctor about myeloma and how the doctor plans to treat the disease.** This will help you to know more about the disease and treatment. It will help you to be involved and make decisions.

- What do my blood tests show? How do my results compare to "normal"?
- When will I need to take these tests again?
- When do you think I will need treatment?
- What kind of treatment do you think I will need?
- Is there a clinical trial that might help me?
- What can I do to help deal with side effects?
- What side effects should I expect from treatment?
- What do you think will happen with my myeloma in the future?
- Should I change my daily routine?
- How many myeloma patients do you have?
- Will my treatment be paid for by Medicare or my other health plan?

**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 friend with you to the doctor. The person can listen, take notes and offer support. Some patients find it easier to tape-record information from the doctor and listen to the tape at home.

Patients and their families, or caregivers, who are unsure about treatment may want to get a second opinion.

## Talking with Caregivers, Family and Friends

**Myeloma patients should talk with their caregivers, family and friends about how they feel.** They can share what they know about the disease. When family and friends know about myeloma and its treatment they may worry less.

# Taking Care of Yourself

**Here are more ways myeloma patients can take care of themselves:**

- Keep all appointments with the doctor.
- Follow the doctor's advice for preventing infection.
- Eat healthy foods each day. It is okay to eat four or five smaller meals if you want.
- Contact your doctor if you have pain or other side effects, even if they occur in between planned visits
- Don't smoke — if you do, get help to quit.
- Get enough rest and exercise. Talk with your doctor before starting an exercise program.

# Medical Terms

**Albumin**
A protein found in blood.

**Antibiotics**
Drugs that are used to treat infections. Penicillin is one type of antibiotic.

**Antibodies**
These are proteins made by plasma cells. Antibodies help to fight infection in the body.

**Bence Jones protein**
A protein made by myeloma cells. It is found in the urine of many patients with myeloma. It is also called "light chains" protein.

**Beta 2-microglobulin**
Beta 2-microglobulin is a cell protein that enters the plasma. The amount of beta 2-microglobulin can be measured. It is used to estimate the patient's myeloma. A very low level is better than a very high level.

# Medical Terms

**Bone marrow biopsy**
A procedure to remove marrow cells and examine them to see if they are normal. A sample of marrow is removed from the hip bone or breast bone. The sample is looked at under a microscope.

**Chemotherapy or drug therapy**
Treatment with drugs or medications to kill cancer cells.

**Chromosomes**
Human cells contain 23 pairs of structures called chromosomes. The chromosomes are made up of genes. Genes give the instructions that tell each cell what to do. The number or shape of chromosomes may be changed in blood cancer cells.

**Clinical trials**
Studies that use volunteers to test new drugs, treatments, or new uses for approved drugs or treatments. There are 3 phases of clinical trials. Phase I trials are done to find the right dose for a drug. Phase I trials also test the safety of the drug. Phase II trials test how well the new treatment works. Phase III trials compare the new treatment to existing treatments.

# Medical Terms

**FISH**
Fluorescence in situ hybridization. A lab test to detect a specific chromosome or gene.

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

**Immunoglobulins**
These are proteins that fight infection.

**Light chains**
A part of the M protein in myeloma. M protein (like normal immunoglobulin) is made up of two heavy (larger) chains and two light (smaller) chains. The M protein and the light chains in the myeloma cells leave the cells and enter the blood. The light chains are small enough to pass through the kidney and enter the urine, where they can be detected. See "Bence Jones protein."

**Lymphocyte**
A type of white blood cell. Some lymphocytes become plasma cells. Plasma cells make antibodies to fight infection. Myeloma is a cancer of new plasma cells.

# Medical Terms

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

**M protein or M spike**
Myeloma cells make a protein called monoclonal immunoglobulin. This protein, also called M protein, enters the blood. The amount of M protein in the blood can be measured. It is used to estimate the extent of the myeloma.

**Platelet**
Type of blood cell that helps prevent bleeding by causing plugs to form.

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

**Refractory myeloma**
Myeloma that has not responded to initial treatment. Refractory disease may be disease that is getting worse or stable disease (not worsening).

# Medical Terms

**Relapsed myeloma**

Myeloma that responded to treatment but then begins to progress.

**Stem cell**

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

**White cell**

A type of blood cell that helps the body to fight infection.

# The Leukemia & Lymphoma Society Is Here to Help

The Leukemia & Lymphoma Society has chapters around the nation. The Society's chapters offer support groups and can also arrange for a myeloma patient to talk with another person who has myeloma. 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.

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



**Questions?** Contact an **Information Specialist** at **The Leukemia & Lymphoma Society** at **www.LLS.org** or **800-955-4572**.

# Notes

# Notes

For more information, please contact:

or:

Home Office

1311 Mamaroneck Avenue, Suite 310

White Plains, NY 10605

Information Resource Center (IRC) 800.955.4572

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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*Fighting Blood Cancers*

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