



Resistant Chronic Myeloid Leukemia

A GUIDE FOR PATIENTS & CAREGIVERS



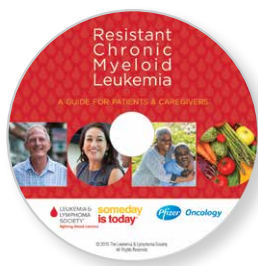
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DVD is on the inside back cover:

The *Resistant Chronic Myeloid Leukemia* DVD features the stories of three patients, with expert commentary from doctors who specialize in chronic myeloid leukemia treatment.



Introduction

Leukemia is a cancer of the bone marrow and blood. There are 4 main types:

- Acute myeloid leukemia (AML)
- Acute lymphoblastic leukemia (ALL)
- Chronic myeloid leukemia (CML)
- Chronic lymphocytic leukemia (CLL)

Although much progress has been made in treating all forms of leukemia, sometimes the cancer does not respond well to the treatment. Or a treatment may work at first, but then becomes less effective. In these cases, the cancer is said to be *resistant* to treatment. Some patients may start on a medication that is not right for them because it causes side effects that are uncomfortable or intolerable. In these cases the cancer is said to be *intolerant* to treatment. This booklet and DVD focus on people who have CML that is resistant or intolerant to treatment.



Even if CML is resistant or intolerant, it can still be treated. Medications for CML can improve symptoms and prolong survival. There are also many ways a person with CML can maintain a good quality of life.

This booklet and DVD program will help you or a loved one learn about:

- Why CML is sometimes resistant to treatment
- Why some patients may not be able to tolerate a medication
- Treatments that might help
- Why it is important to take your CML medication exactly as prescribed
- Ways to maintain a good quality of life

Did You Know?

The word “leukemia” comes from Greek words for “white” and “blood.” White blood cells help the body fight off infections. Leukemia weakens this defense system and causes other health problems.

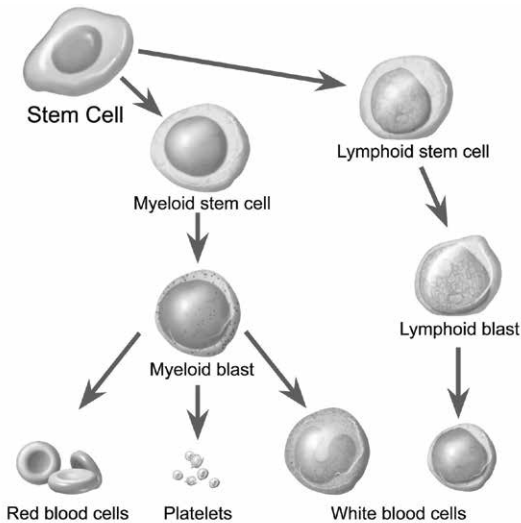


A Closer Look at CML

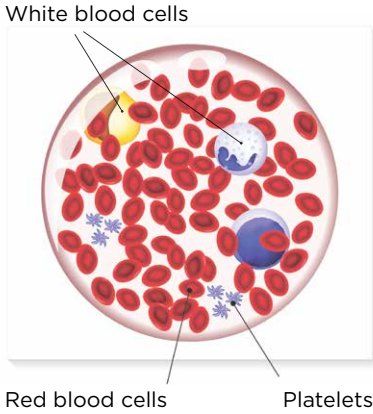
To better understand CML, you need to know a little about the cells in your blood. There are 3 types of blood cells:

- Red blood cells carry oxygen to all the parts of the body
- Platelets help form blood clots to slow or stop bleeding
- White blood cells help the body fight off infections

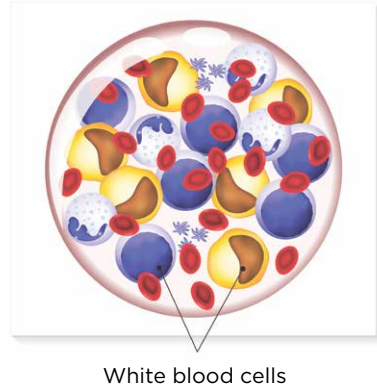
Blood cells are made by *stem cells* in the bone marrow. These stem cells can mature in two ways. Some become *myeloid* stem cells, which can then develop into red blood cells, platelets, or white blood cells. *Lymphoid* stem cells produce a different set of white blood cells.



Normal Blood



Leukemic Blood



Leukemias are named for the type of stem cells affected:

- Myeloid leukemias start in myeloid cells
- Lymphoid leukemias start in lymphoid cells

Leukemia is also named for how quickly it develops. *Acute* leukemia usually develops quickly and people know they are ill. *Chronic* leukemia usually develops more slowly. At first people with a chronic leukemia may not feel sick. But if they are not treated, the leukemia will worsen and the person will begin to have symptoms.

CML, therefore, is a chronic form of leukemia that affects myeloid stem cells. You may also hear CML called “chronic myelogenous leukemia,” “chronic granulocytic leukemia,” or “chronic myelocytic leukemia.”



What Causes CML?

The cause of CML and other types of leukemia is not yet known. But we do know that CML results from a change (called a *mutation*) in the genetic code of a myeloid stem cell. The mutation is “acquired,” which means it was not there when you were born. The name of the mutation involved with CML is the *BCR-ABL* cancer gene, which is also known as the “Philadelphia chromosome.” Tests can detect whether you have this type of mutation.

For more information, see the booklet “The CML Guide: Information for Patients and Caregivers,” available at www.LLS.org/publications or by calling toll-free (800) 955-4572.

CML tends to grow slowly at first, and it mostly affects adults. About 6,000 people in the U.S. are diagnosed with CML each year. About half of these people are older than 65.

Talking With Your Doctor

Try to be as open and honest with your doctor—or doctors—as possible about all of the physical and emotional issues you might be dealing with.

It’s also okay to ask questions—even a lot of questions! Your doctors want to help, and they want you to understand as much as you can.

Ask for an interpreter if you or a loved one does not speak English or is not comfortable with English.

More information about talking with healthcare providers can be found at www.LLS.org.

A photograph of a doctor with a grey beard and glasses, wearing a white lab coat over a red tie and a stethoscope. He is looking down at a clipboard held by a patient. The patient's hands are visible, pointing at the document. The background is a plain wall with a framed picture.

CML tends to grow slowly at first, and it mostly affects adults. About 6,000 people in the U.S. are diagnosed with CML each year.



Three Phases of CML

CML has three phases. Most often, a person learns that he or she has CML in the early “chronic” phase, but sometimes a diagnosis is made at a later stage.

Chronic Phase. People in this phase may have few or no symptoms. Prompt treatment may bring blood cell counts back to normal and eliminate any symptoms. Infections or bleeding (e.g., from cuts or bruises) are uncommon in this phase. The goal of treatment is to stay in the chronic phase. Patients with resistant CML often remain in this phase if they get proper treatment.

Accelerated Phase. In this phase, the levels of blood cells become higher or lower than normal. In addition, immature blood cells called “blasts” are present in the blood or bone marrow. People in this phase may feel tired, they may develop anemia from a lack of red blood cells, and their spleen may become enlarged.

Blast Crisis. In this phase, the number of blast cells increases in both bone marrow and blood. In addition, levels of red blood cells, platelets, and white blood cells can be very low. Patients may have periods of bleeding (from injuries, for example) or infections. Other symptoms can include tiredness, shortness of breath, abdominal pain, bone pain, and/or spleen enlargement.



A Closer Look at Resistance and Intolerance

Patients who start with a specific treatment for CML may find that the treatment is not right for them. Sometimes this is because the medication causes side effects that are uncomfortable or intolerable. A given treatment may also be ineffective if a patient does not take it as prescribed.

Sometimes a medication does not work as well as it could because genetic mutations allow the CML to slowly adapt to the medication. This type of resistance can be due to a number of specific mutations in the *BCR-ABL* cancer gene. Often patients are tested for these mutations if they stop responding to an initial treatment.

For more information, see the booklet “The CML Guide: Information for Patients and Caregivers,” available at www.LLS.org/publications or by calling toll-free (800) 955-4572.

It is important to talk to your doctor if you are not tolerating your current therapy, and to discuss any other reasons you may not be taking your medications as prescribed.



Doctors Who Treat Leukemia

Here are some of the healthcare professionals who may be part of your treatment team.

Hematologists are doctors who specialize in treating blood disorders.

Oncologists are doctors who specialize in treating cancer.

Pathologists are doctors who diagnose cancer and other kinds of diseases using tests and laboratory tools.

Hematopathologists are pathologists who specialize in identifying different kinds of diseases.

Palliative care clinicians focus on treating symptoms and restoring a good quality of life.

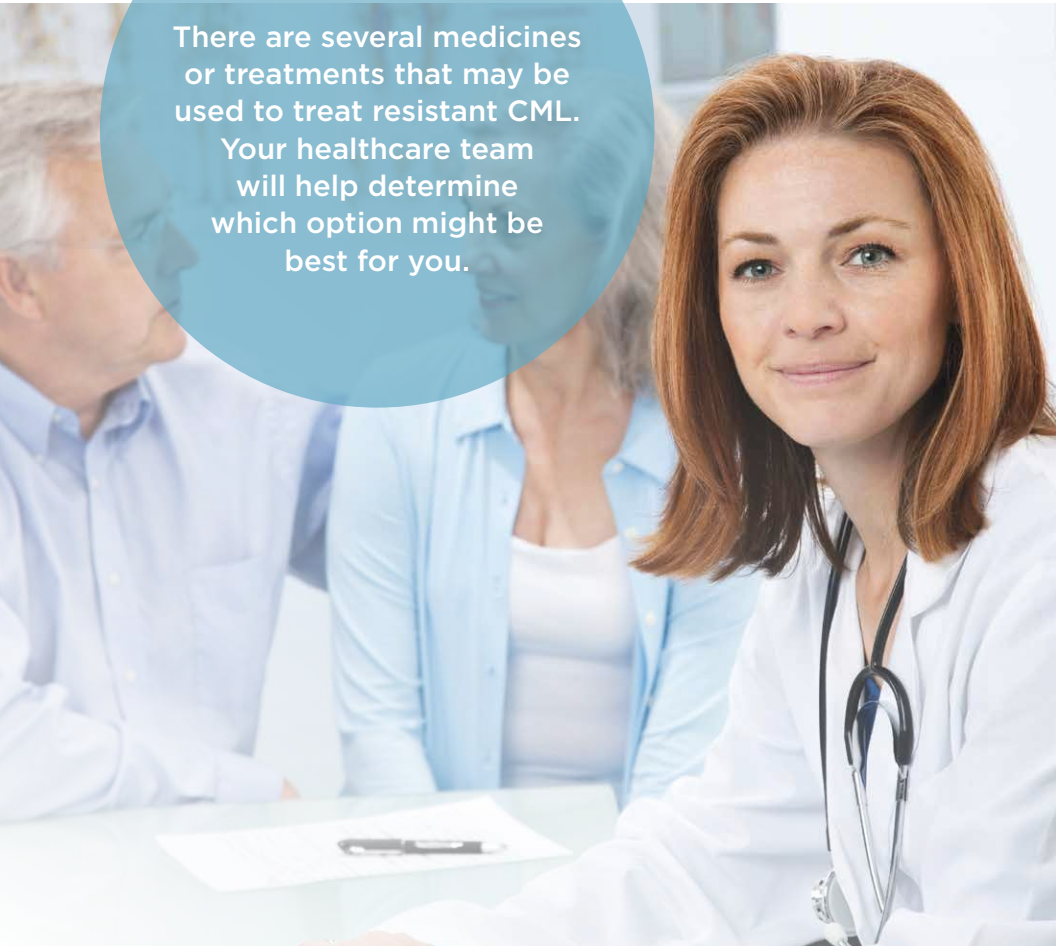


Treatment Options For CML Patients Who Are Resistant or Intolerant to Prior Treatment

Treatments

There are several medicines or treatments that may be used to treat resistant CML.

Your healthcare team will help determine which option might be best for you.



There are several different treatment options for intolerant or resistant CML. Your healthcare team will help determine which treatment option might be best for you.

Targeted therapies (called tyrosine kinase inhibitors or TKIs).

These medicines specifically block the molecules made by the *BCR-ABL* mutation. Resistance to this type of drug seems to be caused by changes in the genes of the CML cells. If this occurs, your doctor may be able to increase your treatment dose or switch you to another targeted medicine that might work better. TKIs currently used to treat CML are taken by mouth as pills. It is important not to skip any pills unless instructed by your doctors. TKIs do not cure CML, but they can keep it under control for most patients.

Other treatment options. One treatment option includes an antineoplastic inhibitor, which prevents the growth and spread of cancerous cells. Stem cell transplants involve an IV infusion of stem cells into the patient from a healthy “matched” donor, who may or may not be related to the patient.

Clinical trials. These are careful studies done by doctors to test new drugs or treatments, or new uses for approved drugs or treatments. There are many clinical trials that combine several drugs in new sequences or dosages. *See page 13 for more details.*

Whichever treatment path you choose, you and your healthcare team will work together to review your treatment options. No two people—and no two cancers—are exactly alike, so treatment choices vary from patient to patient.

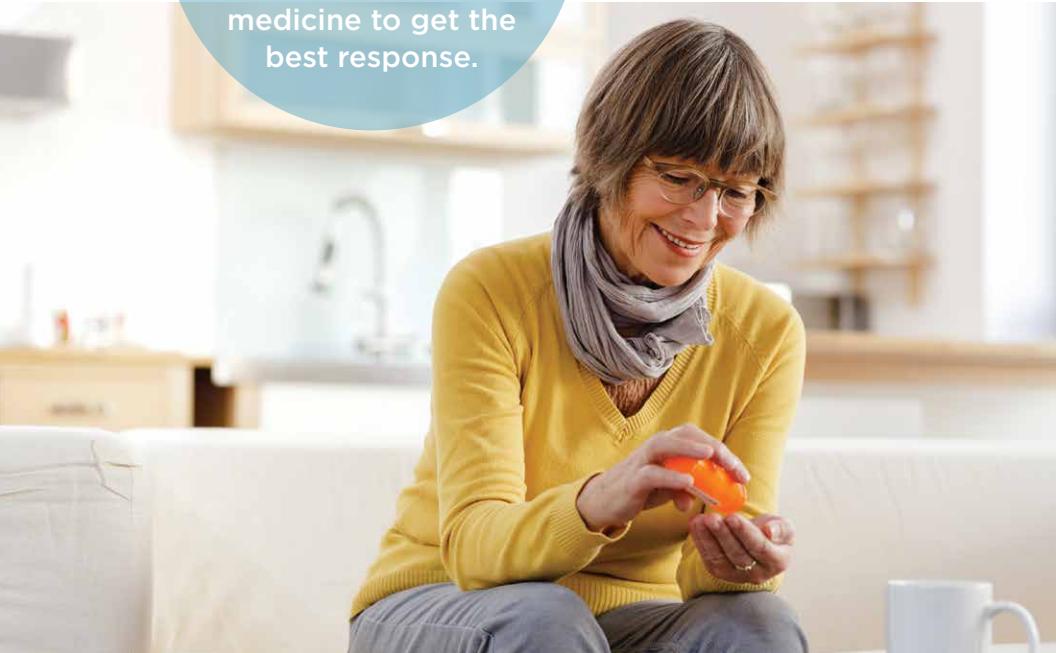
All treatments for CML can involve side effects, which can range from mild to severe (e.g., tiredness, itching, vomiting, risk of infections). Even though some drugs work in similar ways, they may cause different side effects. Your healthcare team will work with you to manage these side effects.



Getting the Most From CML Treatments

CML drugs can be very effective. Take your CML medicine exactly as prescribed by the doctor to get the best treatment benefit. It is important to take the right dose, at the right time, and carefully follow other directions, such as whether to take the medicine with food or not. Talk to your doctor if you are finding it hard to keep track of when to take your medicine and if you are not tolerating the medicine for any reason.

A CML drug has the potential to work if you take it as prescribed. It is important to continue taking your medicine to get the best response.






Clinical Trials

A clinical trial is a research study conducted by doctors. A treatment or drug must be studied in clinical trials before it can be considered for approval by the government. The aim of a cancer clinical trial is to:



- Study a new drug, or a new way to use an approved drug
- Compare a new treatment with a standard treatment to find out which one works better and/or has fewer side effects

If you are interested in a clinical trial, you can find more information in many ways. You can talk to your doctor or talk to an Information Specialist at The Leukemia & Lymphoma Society (LLS). You can search for a trial through the LLS website (www.LLS.org/clinicaltrials), or visit the government's clinical trial website (www.clinicaltrials.gov). *See Resources and Information on page 24 for more information.*



People with any kind of cancer need to organize their lifestyles in ways that enhance their physical and mental well-being.



Living Well With Resistant or Intolerant CML

There are many actions you can take to cope if you are resistant or intolerant to your current CML treatment. Each person, and each situation, is different, so tailor the following suggestions to meet your own needs and goals. People with any kind of cancer need to organize their lifestyles in ways that enhance their physical and mental well-being.

Eat foods recommended by your healthcare provider or a dietitian. Cancer or cancer therapies can change your appetite or make eating difficult. Avoid “fad” diets and unproven supplements. Always consult your healthcare provider before taking any supplements because they may interact with your treatment.



Work with your healthcare team to understand how to stay physically active. It can be hard to exercise if you feel tired, but even mild exercise can be good for both your body and your mind. Take it slowly. You may find you can do a little bit more every day.



Pay attention to your moods. It is normal to feel a range of emotions when faced with CML. But if your mood or emotions become extreme, it can be more difficult to stay healthy. If you are concerned, talk to your healthcare provider because there are many ways to successfully reduce anxiety and relieve depression.



Managing Tiredness

Cancer and its treatment can be exhausting. Here are some tips that might help:

- Stay active or start a gradual program to increase muscle tone and strength
- Drink plenty of water and eat a healthy diet
- Plan activity for times of the day when you feel most energetic
- Ask for help from family and friends
- If you have anemia (low blood iron levels), have it treated by a healthcare provider
- Get plenty of sleep





Finding Support

Having CML that is resistant or intolerant to treatment can impact every part of your life: family, work, finances, and relationships. It can be very helpful to have people around you to help out with daily chores such as shopping, cooking, and cleaning. You may also find comfort in having at least one person you can be completely open and honest with—someone to whom you can tell anything.

Your healthcare provider may offer a referral to professionals who are familiar with the needs of cancer patients. These professionals might be social workers, nurses, or patient advocates. These people can help you navigate the healthcare system, or arrange for childcare or transportation. It can also be comforting and helpful to meet others who are coping with CML. Support groups can meet in person, by phone, or over the Internet. *See Resources and Information on page 22 for more information.*





Paying for Care

Treating CML can be expensive. The costs can be a burden for some people and may affect the medical decisions that you and your doctor make. Be sure to ask about costs and talk openly about them before and during treatment.

It can be hard to understand the details of insurance policies (whether they are from a private company or the government). If you need help, ask for it. Your healthcare team may be able to suggest ways to help reduce or manage medical costs, or direct you to support services and resources for cancer patients and their families. For more information about managing costs, go to www.LLS.org/finances or www.cancer.net/managingcostofcare.





Tips for Caregivers

When a loved one has CML that is resistant or intolerant to treatment, you naturally want to do everything you can to help. You can do this in many ways, including:

- Be the patient's advocate. Write down questions to ask during healthcare visits and take notes at appointments. Two sets of ears are better than one!
- Help with household chores, cooking, or childcare.
- Learn all you can about CML so you know what to expect.
- Organize or manage the medical and financial paperwork.
- Work with the patient to keep track of medications, medical appointments, and treatment schedules.
- Watch for signs of depression or personality changes in the person with CML and discuss any concerns with the doctor.
- Help the patient cope by listening carefully, asking questions, and gently offering your own perspective.



Caregivers must also care for themselves. Do not give up the things that you love. It is OK to take time for yourself!

Keep in mind, however, that the added responsibilities and work involved in supporting someone with cancer can be overwhelming.

That is why caregivers must also care for themselves. If you “burn out,” or develop your own physical or mental difficulties, you will not be able to care as well for the person with CML. Here are some suggestions that may help:

- Focus on the positive impact your support is having.
- Give some tasks to other people to lighten your load.
- Stay healthy by eating right, exercising, and finding time to do things you enjoy.
- Talk with other caregivers, or join a support group.
- Ask for help from friends or family—many people are happy to help if asked.
- Do not give up the things that you love. It is OK to take time for yourself!



Caregivers can find a wealth of information and support from some of the organizations listed at the back of this booklet.



The Road Ahead for Patients

In this booklet you have learned that resistant CML can be managed with the right treatments. Just because your CML is resistant or intolerant to certain drugs does not mean that your CML is advancing. Remember: There are many treatment options available and research in the area of resistant CML is ongoing. By reading this booklet, watching the DVD and learning more about resistant CML, you are moving in a positive direction and taking steps to stay as healthy as possible.

You can use the information in this booklet to begin charting your own course.

By working with your healthcare team and your personal support network, you can give yourself the best chance of staying physically and emotionally healthy.





Resources and Information

The Leukemia & Lymphoma Society (LLS) offers free information and services for patients and families affected by blood cancers. This section of the booklet lists various resources available to you. Use this information to learn more, to ask questions, and to make the most of your healthcare team.

For Help and Information

Consult with an Information Specialist

Information Specialists are master's level oncology social workers, nurses and health educators. They offer up-to-date disease, treatment and support information. Language services are available.

For more information, please

- Call: (800) 955-4572 (Monday through Friday, 9 a.m. to 9 p.m. ET)
- Email: infocenter@LLS.org
- Live chat: www.LLS.org/informationsspecialists

Free Information Booklets

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

Telephone/Web Education Programs

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

Co-Pay Assistance Program

LLS offers insurance premium and medication co-pay assistance for certain eligible patients.

For more information, please

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

Community Resources and Networking

Online Blood Cancer Discussion Boards and Chats

Online discussion boards and moderated online chats can help cancer patients to reach out, share information and provide and receive support. For more information, please visit www.LLS.org/discussionboard or www.LLS.org/chat.

LLS Chapters

LLS offers community support and services in the United States and Canada including the *Patti Robinson Kaufmann First Connection Program* (a peer-to-peer support program), in-person support groups and other helpful resources.

For more information about these programs or to contact your chapter, please

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

Other Helpful Organizations

LLS offers an extensive list of resources for patients and families. There are resources that provide help with financial assistance, counseling, transportation, locating summer camps and other needs. For more information, please visit www.LLS.org/resourcedirectory.

Clinical Trials (Research Studies)

Clinical trials provide new treatments for patients with CML. Patients can learn about clinical trials and how to access them.

For more information, please

- Call: (800) 955-4572 to speak with an LLS Information Specialist who can help conduct a personalized clinical trial search
- Visit: www.LLS.org/clinicaltrials

Advocacy

LLS enlists volunteers to advocate for policies and laws to get new treatments approved and improve access to quality medical care.

For more information, please

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

Additional Help for Specific Populations

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

Language Services

Let your doctor know if you need a language interpreter or other resource, such as a sign language interpreter. Often, these services are free.

Children

CML is rare in children. Families face new and unfamiliar treatments and care protocols. The child, parents and siblings may all need support.

For more information, please

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

Select Childhood Blood Cancer and choose
Coping With Childhood Leukemia and Lymphoma.

Information for Veterans. Veterans with CML who were exposed to Agent Orange while serving in Vietnam may be able to get help from the United States Department of Veteran Affairs (VA). For more information, call the VA at (800) 749-8387 or visit www.publichealth.va.gov/exposures/agentorange.

World Trade Center Survivors

People involved in the aftermath of the 9/11 attacks and subsequently diagnosed with a blood cancer may be eligible for help from the World Trade Center (WTC) Health Program. People offered help include

- Responders
- Workers and volunteers who helped with rescue, recovery and cleanup at the WTC-related sites in New York City (NYC)
- Survivors who were in the NYC disaster area, lived, worked, or were in school in the area
- Responders to the Pentagon and the Shanksville, PA crashes

For more information, please

- Call: WTC Health Program at (888) 982-4748
- Visit: www.cdc.gov/wtc/faq.html

Depression

Treating depression has benefits for cancer patients. Seek medical advice if your mood does not improve over time—for example, if you feel depressed every day for a two-week period.

For more information, please

- Call: National Institute of Mental Health (NIMH) at (866) 615-6464
- Visit: NIMH at www.nimh.nih.gov, enter “depression” in the search box

Additional Resources

American Cancer Society

www.cancer.org

Cancer Support Community

www.cancersupportcommunity.org

National Cancer Institute

www.cancer.gov

Credits

Resistant Chronic Myeloid Leukemia was made possible through the expertise, funding, time, and efforts of many contributors.

PRESENTER

The Leukemia & Lymphoma Society

The Leukemia & Lymphoma Society's (LLS) mission is to cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families. Our mission is carried out through research, education and patient services.

LLS is the world's largest voluntary health organization dedicated to developing better outcomes for blood cancer patients, investing more than \$1 billion in blood cancer research since its inception 65 years ago.

LLS-sponsored research has led to groundbreaking improvements in treating the more than 1 million Americans affected by blood cancers. Our Key Priorities will ensure that: *The Leukemia & Lymphoma Society helps blood cancer patients live better, longer lives.*



FUNDING SUPPORT

Pfizer

Pfizer Oncology is committed to the discovery, investigation and development of innovative treatment options to improve the outlook for cancer patients worldwide. Our strong pipeline of biologics and small molecules, one of the most robust in the industry, is studied with precise focus on identifying and translating the best scientific breakthroughs into clinical application for patients across a wide range of cancers. By working collaboratively with academic institutions, individual researchers, cooperative research groups, governments, and licensing partners, Pfizer Oncology strives to cure or control cancer with breakthrough medicines, to deliver the right drug for each patient at the right time. For more information, please visit www.Pfizer.com.



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By reading this booklet, watching the DVD and learning more about resistant CML, you are moving in a positive direction and taking steps to stay as healthy as possible.



Resistant Chronic Myeloid Leukemia

A GUIDE FOR PATIENTS & CAREGIVERS

There are 4 main types of leukemia. One of these is called *chronic myeloid leukemia*, or CML. Although much progress has been made in treating CML, sometimes it does not respond to the treatment (*resistant CML*).

This booklet and DVD are for patients with this type of leukemia. CML that is resistant or intolerant can still be treated. Options exist that may help patients, by improving symptoms and prolonging survival. There are also many ways that a person with resistant or intolerant CML can maintain his or her physical and emotional health.

This booklet will help you or a loved one learn about:

- Why CML is sometimes resistant to treatment
- Why some patients may not be able to tolerate a medication
- Treatments that might help
- Why it is important to take your CML medication exactly as prescribed
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