

## Preview of the Medifocus Guidebook on: Chronic Lymphocytic Leukemia

Updated July 3, 2019



This document is only a SHORT PREVIEW of the **Medifocus Guidebook on Chronic Lymphocytic Leukemia**. It is intended primarily to give you a general overview of the **format and structure** of the Guidebook as well as select pages from each major Guidebook section listed in the Table of Contents.

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# 1 - Background Information

## Introduction

Chronic or life-threatening illnesses can have a devastating impact on both the patient and the family. In today's new world of medicine, many consumers have come to realize that they are the ones who are primarily responsible for their own health care as well as for the health care of their loved ones.

When facing a chronic or life-threatening illness, you need to become an educated consumer in order to make an informed health care decision. Essentially that means finding out everything about the illness - the treatment options, the doctors, and the hospitals - so that you can become an educated health care consumer and make the tough decisions. In the past, consumers would go to a library and read everything available about a particular illness or medical condition. In today's world, many turn to the Internet for their medical information needs.

The first sites visited are usually the well known health "portals" or disease organizations and support groups which contain a general overview of the condition for the layperson. That's a good start but soon all of the basic information is exhausted and the need for more advanced information still exists. What are the latest "cutting-edge" treatment options? What are the results of the most up-to-date clinical trials? Who are the most notable experts? Where are the top-ranked medical institutions and hospitals?

The best source for authoritative medical information in the United States is the National Library of Medicine's medical database called PubMed®, that indexes citations and abstracts (brief summaries) of over 7 million articles from more than 3,800 medical journals published worldwide. PubMed® was developed for medical professionals and is the primary source utilized by health care providers for keeping up with the latest advances in clinical medicine.

A typical PubMed® search for a specific disease or condition, however, usually retrieves hundreds or even thousands of "hits" of journal article citations. That's an avalanche of information that needs to be evaluated and transformed into truly useful knowledge. What are the most relevant journal articles? Which ones apply to your specific situation? Which articles are considered to be the most authoritative - the ones your physician would rely on in making clinical decisions? This is where *Medifocus.com* provides an effective solution.

*Medifocus.com* has developed an extensive library of *MediFocus Guidebooks* covering a wide spectrum of chronic and life threatening diseases. Each *MediFocus Guidebook* is a

high quality, up- to-date digest of "professional-level" medical information consisting of the most relevant citations and abstracts of journal articles published in authoritative, trustworthy medical journals. This information represents the latest advances known to modern medicine for the treatment and management of the condition, including published results from clinical trials. Each *Guidebook* also includes a valuable index of leading authors and medical institutions as well as a directory of disease organizations and support groups. *MediFocus Guidebooks* are reviewed, revised and updated every 4-months to ensure that you receive the latest and most up-to-date information about the specific condition.

## About Your MediFocus Guidebook

### ***Introduction***

Your *MediFocus Guidebook* is a valuable resource that represents a comprehensive synthesis of the most up-to-date, advanced medical information published about the condition in well-respected, trustworthy medical journals. It is the same type of professional-level information used by physicians and other health-care professionals to keep abreast of the latest developments in biomedical research and clinical medicine. The *Guidebook* is intended for patients who have a need for more advanced, in-depth medical information than is generally available to consumers from a variety of other resources. The primary goal of a *MediFocus Guidebook* is to educate patients and their families about their treatment options so that they can make informed health-care decisions and become active participants in the medical decision making process.

The *Guidebook* production process involves a team of experienced medical research professionals with vast experience in researching the published medical literature. This team approach to the development and production of the *MediFocus Guidebooks* is designed to ensure the accuracy, completeness, and clinical relevance of the information. The *Guidebook* is intended to serve as a basis for a more meaningful discussion between patients and their health-care providers in a joint effort to seek the most appropriate course of treatment for the disease.

### ***Guidebook Organization and Content***

#### **Section 1 - Background Information**

This section provides detailed information about the organization and content of the *Guidebook* including tips and suggestions for conducting additional research about the condition.

#### **Section 2 - The Intelligent Patient Overview**

This section of your *MediFocus Guidebook* represents a detailed overview of the disease or condition specifically written from the patient's perspective. It is designed to satisfy the basic informational needs of consumers and their families who are confronted with the illness and are facing difficult choices. Important aspects which are addressed in "The Intelligent Patient" section include:

- The etiology or cause of the disease
- Signs and symptoms
- How the condition is diagnosed
- The current standard of care for the disease
- Treatment options

- New developments
- Important questions to ask your health care provider

### **Section 3 - Guide to the Medical Literature**

This is a roadmap to important and up-to-date medical literature published about the condition from authoritative, trustworthy medical journals. This is the same information that is used by physicians and researchers to keep up with the latest developments and breakthroughs in clinical medicine and biomedical research. A broad spectrum of articles is included in each *MediFocus Guidebook* to provide information about standard treatments, treatment options, new clinical developments, and advances in research. To facilitate your review and analysis of this information, the articles are grouped by specific categories. A typical *MediFocus Guidebook* usually contains one or more of the following article groupings:

- *Review Articles*: Articles included in this category are broad in scope and are intended to provide the reader with a detailed overview of the condition including such important aspects as its cause, diagnosis, treatment, and new advances.
- *General Interest Articles*: These articles are broad in scope and contain supplementary information about the condition that may be of interest to select groups of patients.
- *Drug Therapy*: Articles that provide information about the effectiveness of specific drugs or other biological agents for the treatment of the condition.
- *Surgical Therapy*: Articles that provide information about specific surgical treatments for the condition.
- *Clinical Trials*: Articles in this category summarize studies which compare the safety and efficacy of a new, experimental treatment modality to currently available standard treatments for the condition. In many cases, clinical trials represent the latest advances in the field and may be considered as being on the "cutting edge" of medicine. Some of these experimental treatments may have already been incorporated into clinical practice.

The following information is provided for each of the articles referenced in this section of your *MediFocus Guidebook*:

- Article title
- Author Name(s)
- Institution where the study was done
- Journal reference (Volume, page numbers, year of publication)

- Link to Abstract (brief summary of the actual article)

*Linking to Abstracts:* Most of the medical journal articles referenced in this section of your *MediFocus Guidebook* include an abstract (brief summary of the actual article) that can be accessed online via the National Library of Medicine's PubMed® database. You can easily access the individual abstracts online via PubMed® from the "electronic" format of your *MediFocus Guidebook* by clicking on the corresponding URL address that is provided for each cited article. If you purchased a printed copy of a *MediFocus Guidebook*, you can still access the article abstracts online by entering the individual URL address for a particular article into your web browser.

## **Section 4 - Centers of Research**

We've compiled a unique directory of doctors, researchers, medical centers, and research institutions with specialized research interest, and in many cases, clinical expertise in the management of the specific medical condition. The "Centers of Research" directory is a valuable resource for quickly identifying and locating leading medical authorities and medical institutions within the United States and other countries that are considered to be at the forefront in clinical research and treatment of the condition.

Inclusion of the names of specific doctors, researchers, hospitals, medical centers, or research institutions in this *Guidebook* does not imply endorsement by Medifocus.com, Inc. or any of its affiliates. Consumers are encouraged to conduct additional research to identify health-care professionals, hospitals, and medical institutions with expertise in providing specific medical advice, guidance, and treatment for this condition.

## **Section 5 - Tips on Finding and Choosing a Doctor**

One of the most important decisions confronting patients who have been diagnosed with a serious medical condition is finding and choosing a qualified physician who will deliver high-level, quality medical care in accordance with currently accepted guidelines and standards of care. Finding the "best" doctor to manage your condition, however, can be a frustrating and time-consuming experience unless you know what you are looking for and how to go about finding it. This section of your *Guidebook* offers important tips for how to find physicians as well as suggestions for how to make informed choices about choosing a doctor who is right for you.

## **Section 6 - Directory of Organizations**

This section of your *Guidebook* is a directory of select disease organizations and support groups that are in the business of helping patients and their families by providing access to information, resources, and services. Many of these organizations can answer your questions, enable you to network with other patients, and help you find a doctor in your geographical area who specializes in managing your condition.

## 2 - The Intelligent Patient Overview

# CHRONIC LYMPHOCYtic LEUKEMIA

### Introduction to Chronic Lymphocytic Leukemia

#### ***What is Chronic Lymphocytic Leukemia?***

The *bone marrow* is the spongy inner part of bones in which all of the different types of blood cells are made. Early (primitive) blood cells are called *stem cells*. As these stem cells mature, they develop into either red blood cells white blood cells (leukocytes), or platelets. There are three main types of white blood cells: *granulocytes*, *monocytes*, and *lymphocytes*.

- Red blood cells are responsible for carrying oxygen from the lungs to all the tissues in the body
- White blood cells are important in fighting infection
- Platelets play a critical role in blood clotting

*Leukemia* is a cancer of the white blood cells that arises from the bone marrow and circulates in the peripheral blood. It is characterized by uncontrolled growth of white blood cells. Leukemia is a disease of the blood cells and does not usually form a solid mass or tumor. Although leukemia starts in the bone marrow, it can spread to the blood, lymph nodes, spleen, liver, central nervous system (CNS) and other organs.

There are four major types of leukemias:

- *Acute myelogenous leukemia* (AML)
- *Chronic myelogenous leukemia* (CML)
- *Acute lymphocytic leukemia* (ALL)
- *Chronic lymphocytic leukemia* (CLL)

The terms "*myelogenous*" and "*lymphocytic*" denote the different types of white blood cells involved. The terms "*acute*" or "*chronic*" refer to the rate of progression of the disease.

*Acute leukemia* is a rapidly progressing disease that results in the accumulation of immature, non-functional cells in the marrow and blood. As a result, the bone marrow often can no longer produce enough normal red blood cells, white blood cells, and platelets. *Chronic leukemia* progresses more slowly and permits greater numbers of more mature functional cells to be made.

According to the American Cancer Society, approximately 15,000 new cases of *chronic lymphocytic leukemia* (CLL) were diagnosed in the United States in 2010 and about 4,400 people died from their disease. For reasons that are not clearly understood, the incidence of CLL is about



2 times higher in males than in females (males = 5.0 cases/100,000; females = 2.5 cases/100,000). The incidence of CLL is much higher in Western countries than in Asian countries such as China and Japan.

Chronic lymphocytic leukemia represents approximately 33% of all leukemias and occurs most frequently in the elderly population. Approximately 66% of patients with CLL are 65 years of age or older and the median age at the time of diagnosis is 72. Chronic lymphocytic leukemia usually does not develop in people under age 40 and is also extremely rare in children. The incidence of CLL in the United States is higher in Caucasians than in African Americans. The average person's lifetime risk of developing CLL is about 1 in 200, although a family history of CLL may raise this risk. From 1999 to 2006, the 5-year overall survival rate of patients with CLL was about 80%.

Chronic lymphocytic leukemia affects a particular type of white blood cells called *B lymphocytes*. For this reason, a more accurate name for this condition is *B-cell chronic lymphocytic leukemia*. Lymphocytes are specialized white blood cells of the immune system that play a major role in the body's ability to fight-off infections. There are 2 major categories of lymphocytes:

- *B lymphocytes* - These lymphocytes are antibody producing cells that are responsible for a type of immunity known as "*humoral immunity*"
- *T-lymphocytes* - These are specialized immune cells responsible for "*cell-mediated immunity*"

Both components of the immune system (humoral immunity and cell-mediated immunity) are needed to combat the wide-spectrum of infections that can be caused by bacteria, viruses, and fungi that may invade the body. Because chronic lymphocytic leukemia is primarily a malignancy of B-lymphocytes, patients with CLL are considered *immunocompromised* and lack the ability to mount an effective immune response to fight-off infections. This is because in patients with CLL, the abnormal (cancerous) lymphocytes grow out of control and eventually overwhelm the healthy white blood cells that help to fight off infections. In fact, infection is a major cause of morbidity and mortality in CLL patients.

## ***What Causes Chronic Lymphocytic Leukemia?***

Chronic lymphocytic leukemia is the only type of leukemia that has not been linked with exposure to ionizing radiation, chemicals, or drugs. Although the exact cause of chronic lymphocytic leukemia (CLL) is currently not known, researchers have recently discovered that certain *mutations* (genetic alterations or errors) that occur in the DNA of normal bone marrow cells can cause these cells to transform into leukemic cells. *Deoxyribonucleic acid* (DNA) molecules carry the genetic information necessary for the organization and functioning of most living cells and control the inheritance of characteristics. *Chromosomes* are structures of compact intertwined molecules of DNA found in the nucleus of cells. Chromosomes contain the cell's genetic information. Humans normally have 46 chromosomes.

*Cytogenetic studies*, special tests that can detect specific genetic mutations of chromosomes, have shown that patients with CLL often have a loss of part of a chromosome. This type of genetic mutation is called a *deletion*. In patients with CLL, the deletion is most often seen on chromosome

11 or 13. Other chromosomal abnormalities can also be detected in patients with CLL such as an extra chromosome 12 (*trisomy 12*).

Chromosomal abnormalities can be found in more than 80% of CLL patients. The most common abnormalities include:

- del 13q - occurs in more than 50% of CLL patients and is usually associated with a good prognosis.
- del 11q and trisomy 12 - each of these abnormalities are found in about 20% of CLL patients.
- del 17p - occurs in less than 10% of CLL patients but is associated with more rapid progression of disease, poor response to treatment, and a short survival time.

## ***Risk Factors for Chronic Lymphocytic Leukemia***

A *risk factor* is anything that increases a person's chances of developing a disease. There are relatively few known risk factors for developing chronic lymphocytic leukemia (CLL). Some of these risk factors include:

- Environmental risk factors - certain herbicides and insecticides used in agriculture have been linked to the development of CLL. Exposure to radiation has not been shown to be a risk factor for CLL.
- Age - most cases of CLL are diagnosed in people 50 years of age or older
- Gender - CLL is more prevalent in males than females by a ratio of 2 to 1.
- Ethnicity - The incidence of CLL in the United States is higher in Caucasians than in African Americans. Among Americans, the lowest incidence of CLL is observed among people of Japanese, Chinese, or Filipino extraction.
- Family History - First-degree relatives of patients with CLL have a higher risk for developing this type of leukemia.

The **Intelligent Patient Overview** in the complete **Medifocus Guidebook on Chronic Lymphocytic Leukemia** also includes the following additional sections:

- **Diagnosis of Chronic Lymphocytic Leukemia**
- **Treatment Options for Chronic Lymphocytic Leukemia**
- **The Role of Complementary and Alternative Therapies in Cancer**
- **Quality of Life Issues in Cancer**
- **Questions to Ask Your Doctor About Chronic Lymphocytic Leukemia**

To Order the Complete **Guidebook on Chronic Lymphocytic Leukemia** [Click Here](#)  
Or Call 800-965-3002 (USA) or 301-649-9300 (Outside USA)

## 3 - Guide to the Medical Literature

### Introduction

This section of your *MediFocus Guidebook* is a comprehensive bibliography of important recent medical literature published about the condition from authoritative, trustworthy medical journals. This is the same information that is used by physicians and researchers to keep up with the latest advances in clinical medicine and biomedical research. A broad spectrum of articles is included in each *MediFocus Guidebook* to provide information about standard treatments, treatment options, new developments, and advances in research.

To facilitate your review and analysis of this information, the articles in this *MediFocus Guidebook* are grouped in the following categories:

- Review Articles - 87 Articles
- General Interest Articles - 30 Articles
- Drug Therapy Articles - 21 Articles
- Clinical Trials Articles - 63 Articles

The following information is provided for each of the articles referenced in this section of your *MediFocus Guidebook*:

- Title of the article
- Name of the authors
- Institution where the study was done
- Journal reference (Volume, page numbers, year of publication)
- Link to Abstract (brief summary of the actual article)

**Linking to Abstracts:** Most of the medical journal articles referenced in this section of your *MediFocus Guidebook* include an abstract (brief summary of the actual article) that can be accessed online via the National Library of Medicine's PubMed® database. You can easily access the individual abstracts online via PubMed® from the "electronic" format of your *MediFocus Guidebook* by clicking on the URI that is provided for each cited article. If you purchased a printed copy of the *MediFocus Guidebook*, you can still access the abstracts online by entering the individual URI for a particular abstract into your computer's web browser.

## Recent Literature: What Your Doctor Reads

Database: PubMed <January 2015 to July 2019>

### Review Articles

1.

#### Relevance of TP53 for CLL diagnostics.

**Authors:** Catherwood MA; Gonzalez D; Donaldson D; Clifford R; Mills K; Thornton P  
**Institution:** Haematology Department, Belfast Health and Social Care Trust, Belfast, UK  
mark.catherwood@belfasttrust.hscni.net. Belfast, UK. Belfast, UK.  
**Journal:** J Clin Pathol. 2019 May;72(5):343-346. doi: 10.1136/jclinpath-2018-205622.  
Epub 2019 Feb 2.  
**Abstract Link:** <http://www.medifocus.com/abstracts.php?gid=HM004&ID=30712002>

2.

#### Management of adverse events associated with idelalisib treatment in chronic lymphocytic leukemia and follicular lymphoma: A multidisciplinary position paper.

**Authors:** Cuneo A; Barosi G; Danesi R; Fagioli S; Ghia P; Marzano A; Montillo M; Poletti V; Viale P; Zinzani PL  
**Institution:** Hematology Section, Department of Medical Sciences, Azienda Ospedaliero-Universitaria, Arcispedale S. Anna, University of Ferrara, Ferrara, Italy. Experimental Medicine, University of Pisa, Pisa, Italy. Bergamo, Italy. Milan, Italy. Torino, Turin, Italy. Italy. Denmark. Studiorum - University of Bologna, Bologna, Italy. Bologna, Italy.  
**Journal:** Hematol Oncol. 2019 Feb;37(1):3-14. doi: 10.1002/hon.2540. Epub 2018 Sep 5.  
**Abstract Link:** <http://www.medifocus.com/abstracts.php?gid=HM004&ID=30187496>

The **Guide to the Medical Literature** in the complete **Medifocus Guidebook on Chronic Lymphocytic Leukemia** includes the following sections:

- Review Articles - 87 Articles
- General Interest Articles - 30 Articles
- Drug Therapy Articles - 21 Articles
- Clinical Trials Articles - 63 Articles

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## 4 - Centers of Research

This section of your *MediFocus Guidebook* is a unique directory of doctors, researchers, medical centers, and research institutions with specialized research interest, and in many cases, clinical expertise in the management of this specific medical condition. The *Centers of Research* directory is a valuable resource for quickly identifying and locating leading medical authorities and medical institutions within the United States and other countries that are considered to be at the forefront in clinical research and treatment of this disorder.

Use the *Centers of Research* directory to contact, consult, or network with leading experts in the field and to locate a hospital or medical center that can help you.

The following information is provided in the *Centers of Research* directory:

- **Geographic Location**

- United States: the information is divided by individual states listed in alphabetical order. Not all states may be included.
- Other Countries: information is presented for select countries worldwide listed in alphabetical order. Not all countries may be included.

- **Names of Authors**

- Select names of individual authors (doctors, researchers, or other health-care professionals) with specialized research interest, and in many cases, clinical expertise in the management of this specific medical condition, who have recently published articles in leading medical journals about the condition.
- E-mail addresses for individual authors, if listed on their specific publications, is also provided.

- **Institutional Affiliations**

- Next to each individual author's name is their **institutional affiliation** (hospital, medical center, or research institution) where the study was conducted as listed in their publication(s).
- In many cases, information about the specific **department** within the medical institution where the individual author was located at the time the study was conducted is also provided.

## Centers of Research

### United States

#### AZ - Arizona

**Name of Author**

Hilal T

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#### CA - California

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The **Centers of Research** in the complete **Medifocus Guidebook on Chronic Lymphocytic Leukemia** includes the following sections:

- Centers of Research for relevant states in the United States
- Centers of Research listed for relevant countries outside the United States

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# 5 - Tips on Finding and Choosing a Doctor

## Introduction

One of the most important decisions confronting patients who have been diagnosed with a serious medical condition is finding and choosing a qualified physician who will deliver a high level and quality of medical care in accordance with currently accepted guidelines and standards of care. Finding the "best" doctor to manage your condition, however, can be a frustrating and time-consuming experience unless you know what you are looking for and how to go about finding it.

The process of finding and choosing a physician to manage your specific illness or condition is, in some respects, analogous to the process of making a decision about whether or not to invest in a particular stock or mutual fund. After all, you wouldn't invest your hard earned money in a stock or mutual fund without first doing exhaustive research about the stock or fund's past performance, current financial status, and projected future earnings. More than likely you would spend a considerable amount of time and energy doing your own research and consulting with your stock broker before making an informed decision about investing. The same general principle applies to the process of finding and choosing a physician. Although the process requires a considerable investment in terms of both time and energy, the potential payoff can be well worth it--after all, what can be more important than your health and well-being?

This section of your Guidebook offers important tips for how to find physicians as well as suggestions for how to make informed choices about choosing a doctor who is right for you.

## Tips for Finding Physicians

Finding a highly qualified, competent, and compassionate physician to manage your specific illness or condition takes a lot of hard work and energy but is an investment that is well-worth the effort. It is important to keep in mind that you are not looking for just any general physician but rather for a physician who has expertise in the treatment and management of your specific illness or condition. Here are some suggestions for where you can turn to identify and locate physicians who specialize in managing your disorder:

- **Your Doctor** - Your family physician (family medicine or internal medicine specialist) is a good starting point for finding a physician who specializes in your illness. Chances are that your doctor already knows several specialists in your geographic area who specialize in your illness and can recommend several names to you. Your doctor can also provide you with information about their qualifications, training, and hospital affiliations.

The **Tips on Finding and Choosing a Doctor** in the complete **Medifocus Guidebook on Chronic Lymphocytic Leukemia** includes additional information that will assist you in locating a highly qualified and competent physician to manage your specific illness.

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## 6 - Directory of Organizations

### **American Cancer Society**

1599 Clifton Road, N.E.; Atlanta, GA 30329  
800-227-2345; 866-228-4327 (TTY)

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

### **American Institute for Cancer Research; Nutrition Hotline**

1759 R St, NW; Washington, DC 20009  
202.328.7744; 800.843.8114

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

### **American Society of Pediatric Hematology/Oncology**

4700 West Lake; Glenview, IL 60025-1485  
847.375.4716

[info@aspho.org](mailto:info@aspho.org)

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

### **Association of Cancer Online Resources**

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

### **Cancer Care**

275 Seventh Avenue; New York, NY 10001  
800.813.4673; 212.712.8400

[info@cancercares.org](mailto:info@cancercares.org)

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

### **Cancer Caring Center**

4117 Liberty Avenue; Pittsburgh, PA 15224  
412.622.1212

[info@cancercaring.org](mailto:info@cancercaring.org)

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

### **Cancer Hope Network**

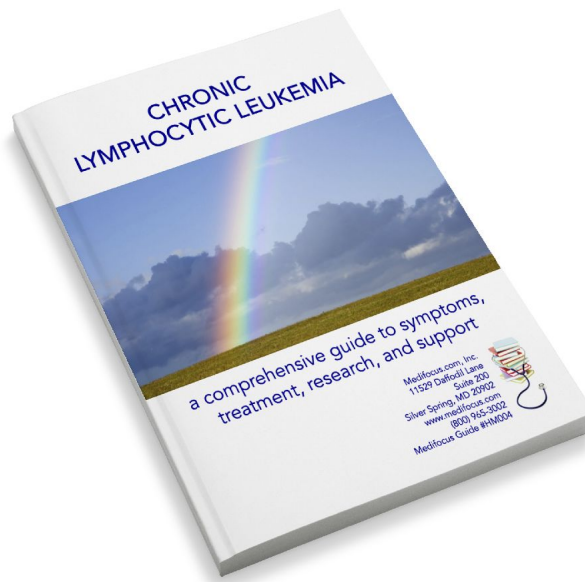
2 North Road; Chester, NJ 07930  
877.467.3638; 908.879.4039

[info@cancerhopenetwork.org](mailto:info@cancerhopenetwork.org)

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

The **Directory of Organizations** in the complete **Medifocus Guidebook on Chronic Lymphocytic Leukemia** includes a list of selected disease organizations and support groups that are helping people diagnosed with Chronic Lymphocytic Leukemia.

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