

# PARTNERS in PROGRESS

An Expert Panel Discussion on Advancing Therapies for Blood Cancers



RESEARCH SCIENTISTS

DOCTORS

NURSES

PATIENTS

BETTER OUTCOMES

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Lymphoma Society**  
*Fighting Blood Cancers*

# Advancing Therapies for Blood Cancers

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*Chief, Division of Leukemia*

John Theurer Cancer Center

Hackensack University Medical Center

Hackensack, NJ

*Associate Clinical Professor of Medicine*

University of Medicine & Dentistry of New Jersey

Newark, NJ



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# The Good News

- There have been advances
- But advances do not come by wishful thinking
- Participation in clinical research trials advance the treatment of blood diseases



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# Steps to Progress

- Basic science:
  - Better understanding of disease
- Basic research:
  - New ideas in treatments, early studies in mouse and other models
- Clinical research:
  - Studying new treatments in humans with a disease



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# Clinical Trials

- Phase I studies
  - Is the treatment safe in humans?
- Phase II studies
  - Is the treatment effective in a particular disease?
- Phase III studies
  - Is the treatment better than the standard treatment?

# Everyone Benefits from Clinical Trials

- Thanks to all the patients and researchers who move treatment forward by participating in clinical research
- For more information contact:
  - [www.LLS.org/clinicaltrials](http://www.LLS.org/clinicaltrials)
  - [www.clinicaltrials.gov](http://www.clinicaltrials.gov)

# Myths and Misconceptions About Clinical Trials

Gail J. Roboz, MD  
*Director, Leukemia Program*  
*Associate Professor of Medicine*  
Weill Medical College of Cornell University  
New York-Presbyterian Hospital  
New York, NY

# In 2010, Few Cancers Can Be Cured

- But less than 10% of patients in the United States participate in clinical trials
- Why?



# Spectacular Successes in Hematologic Malignancies

- Chronic myeloid leukemia (CML)
- Acute promyelocytic leukemia (APL)
- Hodgkin disease
- Childhood acute lymphoblastic leukemia (ALL)
- Hairy cell leukemia (HCL)

**ALL BECAUSE OF CLINICAL TRIALS**

# Clinical Trials Have Many Objectives

- Compare existing treatments
- Provide access to novel treatments
- Compare novel to existing treatments
- Study the effects of an intervention on a group of patients (e.g., the effects of riding an exercise bike on transplant patients)
- Study the characteristics of a group of patients (e.g., quality of life in older leukemia patients)

# **IMPORTANT: Clinical Trials Give Patients the Answers They Want and Need**

- Does X work?
- What are my chances of remission with X?
- How long will my remission last with X?
- What are the most common side effects of X?
- What are the long-term side effects of X?

# People Have Many Concerns About Clinical Trials

- I don't want to be a guinea pig
- I'm too old
- I'm too young
- Clinical trials involve experimental drugs
- Clinical trials are for patients with no treatment options
- You have to pay to get onto a clinical trial
- You get paid to be on a clinical trial



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## More Concerns

- My doctor will be mad at me if I participate
- My doctor will be mad at me if I don't participate
- I don't want to get a placebo
- I don't want to stop my other medications
- Clinical trials won't help me, just other patients
- Privacy—I don't want other people to know details about me

# Whatever Your Concerns...

- Ask your doctors about clinical trials!

# **Maria Baldo, MS, PA-C**

*Senior Physician Assistant, Leukemia Service*  
Weill Medical College of Cornell University  
New York-Presbyterian Hospital  
New York, NY

# Making a Decision About Participating in a Clinical Trial

- Understanding potential risks and benefits
- Understanding rights and responsibilities



# Informed Consent is a Two-Part Process

1. Document
2. Updated study information

# Informed Consent Document

- Purpose
- Duration
- Risks/benefits
- Alternatives to participation
- Confidentiality
- Costs/additional expenses
- Contact information
- Signature



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# Eligibility Criteria

- Disease type
- Patient age
- Stage of disease
- Other treatments used by the patient
- The presence of any other illness or condition



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# Important Questions to Ask Clinical Research Team

- How do the tests/procedures in the study compare with those I would have outside of the trial?
- Will I be able to take my regular medications?
- Who will be in charge of my care?
- What type of follow-up care is part of the study?
- How could being in the study affect my daily life?



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# **John J. Hughes**

MDS Survivor

Clinical Trial Participant

Bayonne, NJ



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# Advancing Therapies for Blood Cancers

Louis J. DeGennaro, PhD  
*Executive Vice President and Chief Mission Officer*  
The Leukemia & Lymphoma Society  
White Plains, NY



# Anyone Can Get Blood Cancer

**In 2010:**

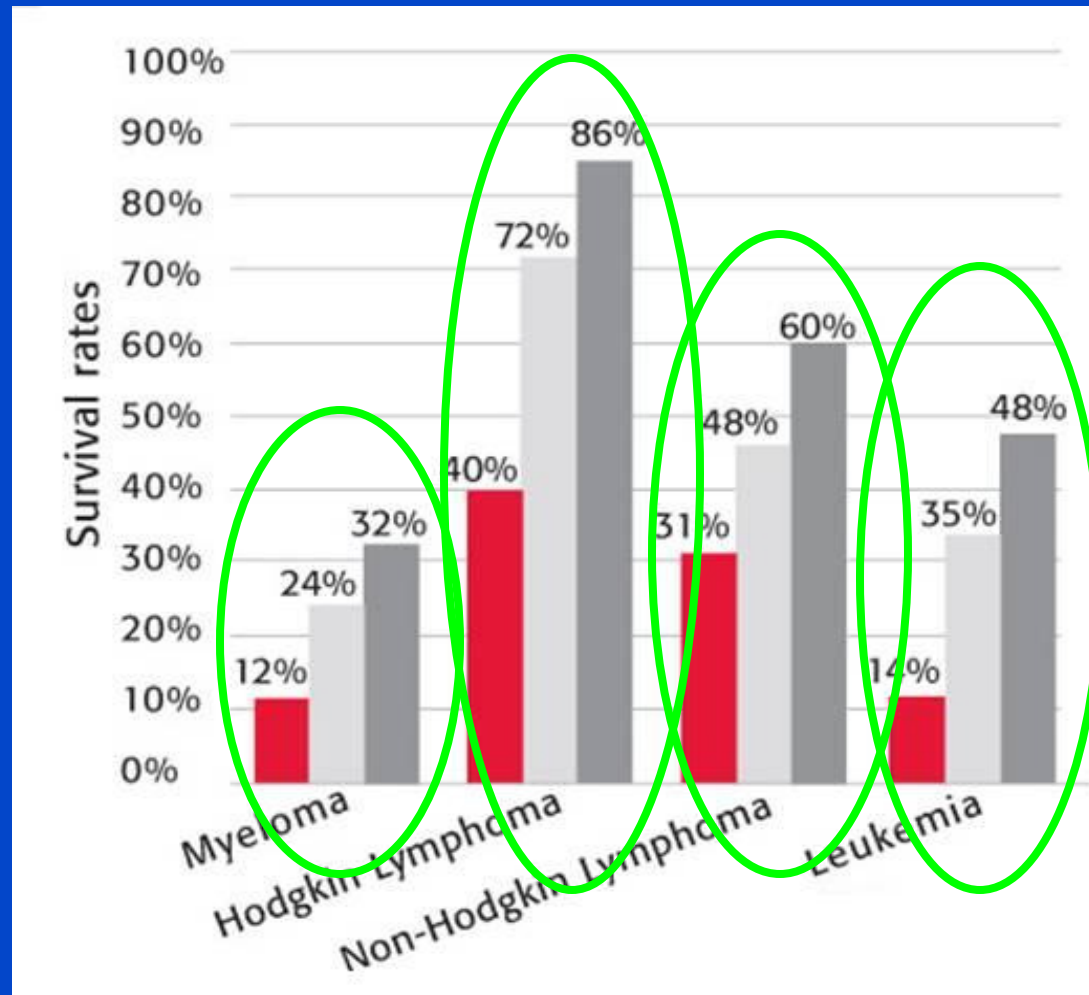
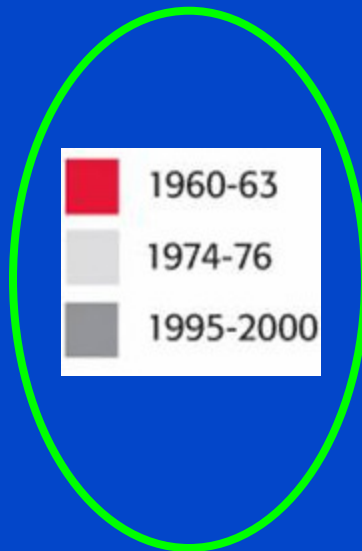
**One million Americans**



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# Research Works!

Survival rates have  
doubled or tripled  
over the last  
4 decades

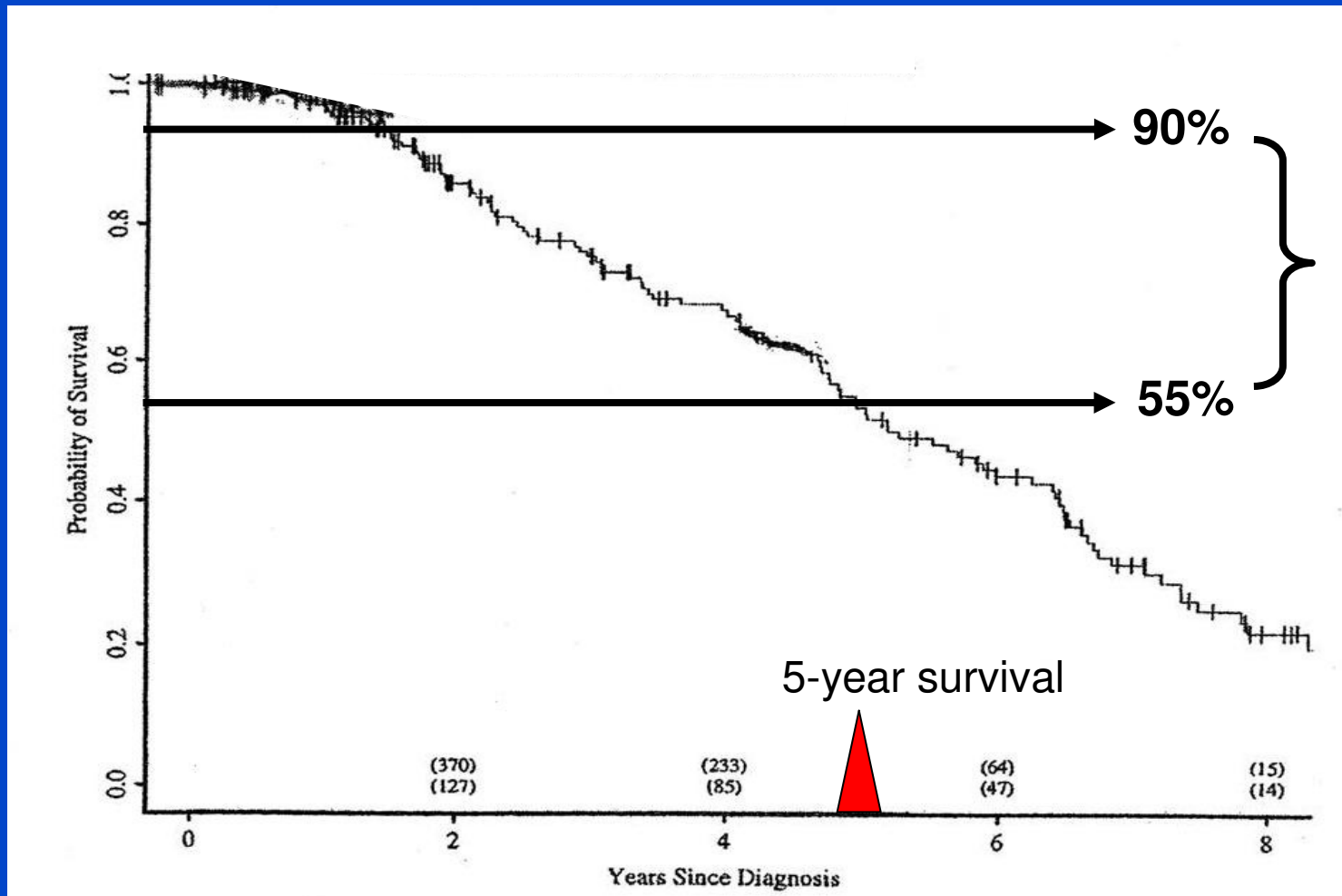






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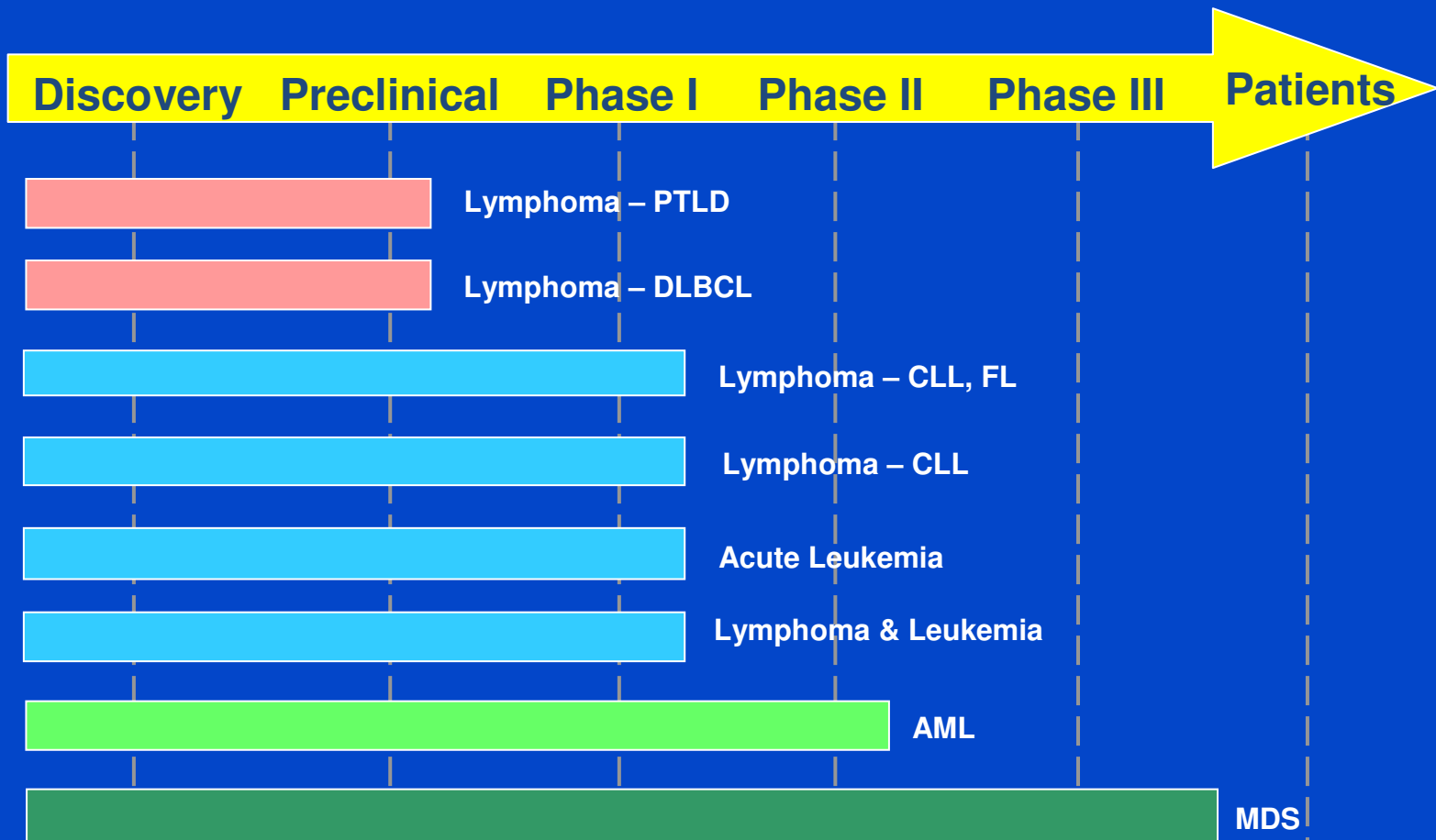
# Research Value Proposition: CML & Gleevec





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# LLS Therapeutic Pipeline



# Partnering With Patients

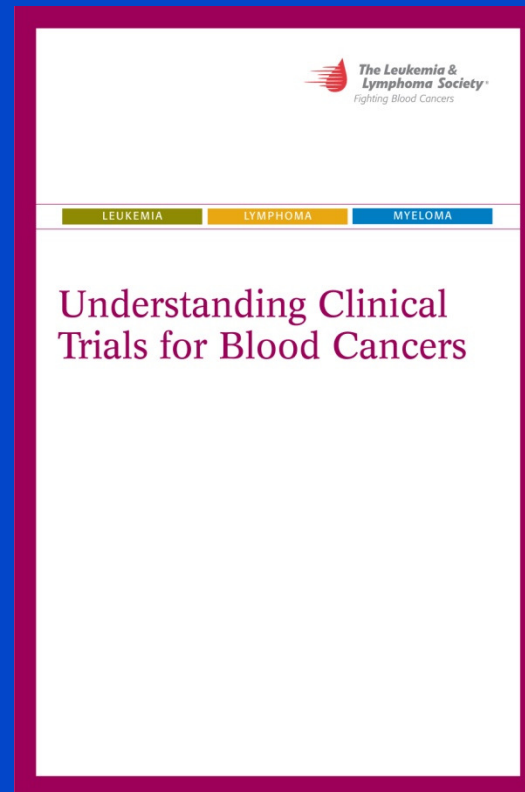
- Comprehensive patient services
  - Education, support groups
  - Financial aid
  - Clinical trial matching service
- State & federal public policy initiatives
- Proven research strategy
- **A sense of urgency**



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# Panel Discussion

# Understanding Clinical Trials for Blood Cancers



[www.LLS.org/freematerials](http://www.LLS.org/freematerials)  
(800) 955-4572



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# TrialCheck®

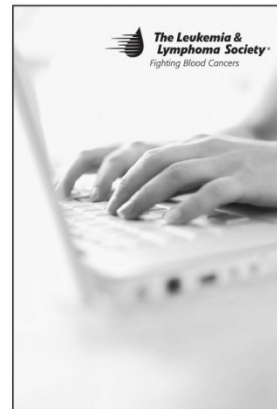


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## ***TrialCheck® A Clinical Trial Search Service***

The Leukemia & Lymphoma Society (LLS) is pleased to offer TrialCheck®, a clinical trial search tool.

After answering a few short questions, healthcare professionals, patients and caregivers can immediately access listings of clinical trials for leukemia, lymphoma, myeloma and other blood cancers. Search results show clinical trials targeted to a patient's diagnosis, disease type and stage, and zip code preference.



A cancer clinical trial is a carefully controlled research study conducted by doctors to improve the care and treatment of cancer patients. Clinical trials are designed to give patients the safest, potentially most effective clinical therapies and follow strict scientific and ethical principles.

**[www.LLS.org/clinicaltrials](http://www.LLS.org/clinicaltrials)  
(800) 955-4572**

# Resources

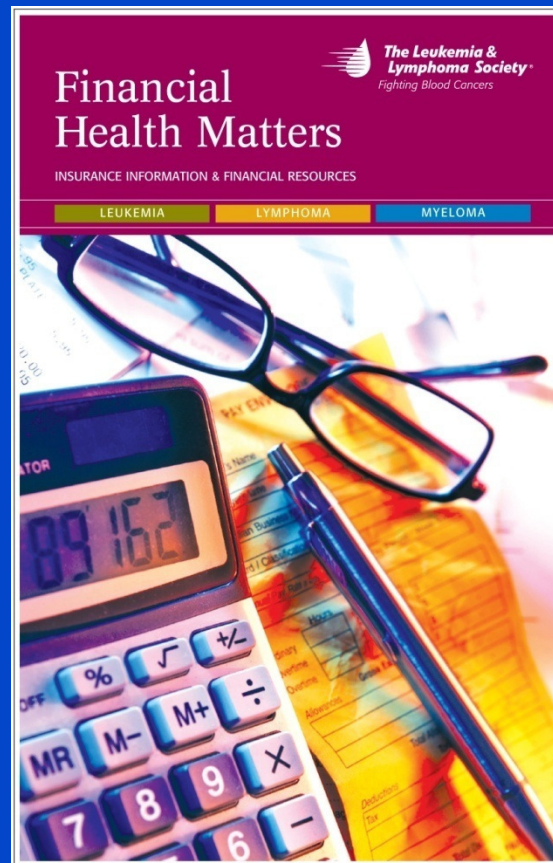
- LLS Patient Financial Aid
  - (800) 955-4572
- LLS Co-Pay Assistance Program
  - [www.LLS.org/copay](http://www.LLS.org/copay)
  - (877) LLS-COPAY
- Medicare Rights Center
  - [www.medicarerights.org](http://www.medicarerights.org)
  - (800) 333-4114
- Cancer Financial Assistance Coalition
  - [www.cancerfac.org](http://www.cancerfac.org)

# Resources

- Cancer Legal Resource Center
  - [www.cancerlegalresourcecenter.org](http://www.cancerlegalresourcecenter.org)
  - (866) THE-CLRC
- Max Foundation
  - [www.maxaid.org](http://www.maxaid.org)
  - (888) 462-9368
- Patient Advocate Foundation
  - [www.patientadvocate.org](http://www.patientadvocate.org)
  - (800) 532-5274



# Financial Health Matters



[www.LLS.org/freematerials](http://www.LLS.org/freematerials)  
(800) 955-4572



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# Question-and-Answer Session



The **Co-Pay Assistance Program** offers financial assistance to qualified patients to help with treatment-related expenses and insurance premiums. Funding is available for chronic myelogenous leukemia (CML), chronic lymphocytic leukemia (CLL), Hodgkin lymphoma, non-Hodgkin lymphoma (NHL), myelodysplastic syndromes (MDS), myeloma and Waldenström macroglobulinemia. Patients may apply online or over the phone with a Co-Pay Specialist.

Toll-free Phone: 1-877-LLS-COPAY

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

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For more information about **Clinical Trials and other LLS programs**, contact: Information Resource Center (IRC)

Toll-free Phone: 1-800-955-4572

Email: [infocenter@lls.org](mailto:infocenter@lls.org)