

**Questions to Ask to  
Make Informed Treatment Decisions**



# Welcome & Introductions



# Questions to Ask to Make Informed Treatment Decisions

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## First, know what you're talking about

- What exactly (!! ) is my diagnosis?
- Is there a standard treatment for my disease?
- How well does the standard treatment work? What are the chances it will cure me? If the treatment doesn't cure me, what exactly will it do? What happens if I don't get treatment?
- What are the expected risks and side effects associated with standard treatment?
- Is there more than one accepted standard for my disease and, if so, how should I choose between them?
- Are you the right doctor for my disease?
- Are there clinical trials available for my disease?

## Success stories in cancer medicine

- Chronic myeloid leukemia (CML)
- Acute promyelocytic leukemia (APL)
- Hodgkin disease
- Breast cancer
- Testicular cancer
- Prostate cancer

**ALL BECAUSE OF CLINICAL TRIALS**

## In 2011, few cancers can be cured

- BUT LESS THAN 10% OF PATIENTS IN THE USA PARTICIPATE IN CLINICAL TRIALS!!!!
- Why????????????????????????????????

## 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 to make me better?
- 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?

## Information

- [LLS.org/clinicaltrials](http://LLS.org/clinicaltrials)
- [Trialcheck.org](http://Trialcheck.org)
- [Clinicaltrials.gov](http://Clinicaltrials.gov)

## But, 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

## 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 DOCTOR ABOUT CLINICAL TRIALS**

**LLS Resources**



**Information Resource Center:** Speak one-on-one with an Information Specialist who can assist you through cancer treatment, financial and social challenges. Please visit: [www.LLS.org/resourcecenter](http://www.LLS.org/resourcecenter)

**What to Ask:** For a list of suggested questions to ask about certain topics, download and print any or all of the following guides at: [www.LLS.org/whattoask](http://www.LLS.org/whattoask)

**Other Helpful Organizations Resource Directory:** LLS is pleased to offer an extensive directory of national and international resources. Please visit: [www.LLS.org/resourcedirectory](http://www.LLS.org/resourcedirectory)

**Education Programs:** LLS sponsors a range of free telephone and web education programs, videos, and local education programs for patients and caregivers. Please visit: [www.LLS.org/programs](http://www.LLS.org/programs)

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## Question and Answer Session

Dr. Roboz's slides are available for download at  
[www.LLS.org/programs](http://www.LLS.org/programs)

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The Leukemia & Lymphoma Society (LLS) offers:

- Live, weekly Online Chats that provide a friendly forum to share experiences and chat with others about anything from the initial phase of diagnosis to treatment and survivorship. Each chat is moderated by an oncology social worker and is password-protected.

- **WEBSITE: [www.LLS.org/chat](http://www.LLS.org/chat)**

- Co-Pay Assistance Program offers financial assistance to qualified cancer patients to help with treatment-related expenses and insurance premiums. Patients may apply online or over the phone with a Co-Pay Specialist.

- **WEBSITE: [www.LLS.org/copay](http://www.LLS.org/copay)**

- **TOLL-FREE PHONE: (877) LLS-COPAY**

For more information about blood cancers and other LLS programs, please contact an LLS Information Specialist.

- **TOLL-FREE PHONE: (800) 955-4572**

- **EMAIL: [infocenter@LLS.org](mailto:infocenter@LLS.org)**