## **ABOUT US**

**Providing** timely access to evidence-based information about lymphomas.

Advancing the patient's right to know the potential risks and benefits of cancer treatments – whether standard, investigational, complementary, or alternative.

regulatory policies developed from a patient's perspective; in ways to improve patient access to effective treatments; and in the encouragement of innovative research in safer more effective treatments supported by government and private investment.

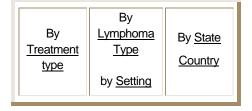


# Visit our website at www.Lymphomation.org

Some Highlights ...

**About Clinical Trials** 

Links to Lymphoma-specific clinical trials in the ClinicalTrials.gov database:



About Expanded Access – Compassionate Use

Help Finding Experts to Consult:

 Find Doctors
 Communicate with Doctors
 Cancer Centers

Guidelines at Diagnosis
Treatment Decisions
Travel for Treatment



Patients Against Lymphoma

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# PATIENTS AGAINST LYMPHOMA

Would a clinical trial be appropriate for me?

A checklist of questions for your doctor ... applies to many health conditions



Patients helping Patients

Linking patients to reputable evidencebased information, and voicing patient perspectives in the fight against lymphoma

## **QUESTIONS**

Are new treatments under study that would be appropriate for me?

Ask this of your treating physician.

Ask this of an independent expert as well.

Try to obtain a consensus that your decision to try a treatment is reasonable and appropriate. Be aware that investigators who are conducting a clinical study can sometimes have unintended intellectual biases.

## WHEN CLINICAL TRIALS MAY BE APPROPRIATE

**Guidelines** prepared by patients for patients

When standard treatments are not expected to cure the disease.

When the investigational therapy provides a potential improvement over standard therapies, such as a possible cure, or management of the disease with fewer side effects.

When investigational therapy has less expected toxicity than available standard treatments.

When your disease does not require immediate treatment – so called watchful waiting – and the investigational treatment is not likely to make standard therapies less effective (preclude them) should they be needed later on.

When you are not responding to standard therapies, and/or cannot tolerate the toxicities associated with them.

When diagnostic tests indicate the characteristics of your disease makes it unlikely that it will respond to standard therapies.

### TREATMENT QUESTIONS

Treatment and initial consults should not be rushed. Ask your doctor or the independent expert you consult to schedule a time that allows for a thorough discussion of all appropriate options. Bring your written questions to this consult, and provide a copy for your doctor.

- What materials or resources can you provide to help me to become informed about the therapies you think most appropriate?
- Does the disease require prompt treatment and why?
- Can the disease be cured with standard or investigational approaches?
- What are the symptoms of the disease, and which indicate a need for treatment?
- What are my treatment choices? What are the pros and cons of each?
- Which standard and investigational treatments do you recommend? Why?
  - Does this treatment over a chance of a cure?
  - o What is the goal of this treatment?
  - What are the chances that the treatment will be successful?
  - o How long will the treatments last?
  - How easy is it to administer, and will it disrupt my normal life or ability to work?
  - o How durable is the response likely to be?
  - What toxicity and/or risks are associated with this treatment?

- Which treatments appear to be safest and less likely to limit future options?
- Can this treatment reduce my chances of benefiting from important subsequent treatments?
- What signs will indicate that the therapy is starting to work or that it is not working?

#### **SIDE EFFECT QUESTIONS**

- What side effects should I expect? And what side effects should I report to you?
- What signs or changes should I report immediately? And how can I best contact you when this happens?
- How will I feel during therapy, and will it affect my normal activities?
- What can I do to minimize risks during therapy?
- Will you prescribe medications to minimize side effects and risks?
- What side effects may I experience that are not dangerous?
- What foods, supplements, procedures, or medications should I avoid during treatment?

#### **TEST QUESTIONS**

- What tests will you order? What do they measure? Will you provide copies?
- How often should I receive these tests?
- What changes or symptoms may indicate the need for tests?
- When is a bone marrow biopsy indicated?
   What steps can you take to minimize discomfort and anxiety associated with this test?
- When frequent imaging tests are required, can MRI be used instead of CT in order to minimize exposures to radiation?
- What test results indicate a need to initiate or change treatment?