

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.

Leading in the effort to achieve 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:

By <u>Treatment type</u>	By <u>Lymphoma Type</u> by <u>Setting</u>	By <u>State</u> <u>Country</u>
-----------------------------	---	-----------------------------------

About Expanded Access – Compassionate Use

Help Finding Experts to Consult:

<u>Find Doctors</u>	<u>Communicate with Doctors</u>	<u>Cancer Centers</u>
---------------------	---------------------------------	-----------------------

Guidelines at Diagnosis

Treatment Decisions

Travel for Treatment



Patients Against Lymphoma

1305 Mason Avenue
Staten Island, NY 10306

Phone: 718-980-0635 | Fax: 801-409-5736
KarlS@Lymphomation.org

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 evidence-based 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 offer a chance of a cure?
 - What is the goal of this treatment?
 - What are the chances that the treatment will be successful?
 - How long will the treatments last?
 - How easy is it to administer, and will it disrupt my normal life or ability to work?
 - 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?