

# How to Find a Cancer Treatment Trial: A 10 Step Guide

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## Introduction

This guide will help you look for a cancer treatment clinical trial. It does not provide medical advice and should not be used in place of advice from your doctor or other members of your health care team. Your health care team and your loved ones, if you wish, can assist you in deciding whether or not a clinical trial is right for you. The decision to take part in a clinical trial is yours alone to make.

### This guide will help you to:

- Gather the information you need to begin your search for a clinical trial.
- Identify Web sites that have lists of open clinical trials. Open trials are those that are accepting eligible people who wish to participate.
- Learn about clinical trials for your type and stage of cancer.
- Ask questions that will help you decide whether or not to take part in a trial.

**Helpful Tip:** *This guide contains links to other Web pages and sites. Links to pages and sites external to the National Cancer Institute (NCI) are included for convenience and informational purposes only. Including these links cannot be taken as an endorsement by NCI of the Web pages and sites. See the [NCI Web site's Disclaimer of Endorsement and Liability](#) policy.*

## A Word About Timing

Some treatment trials will not accept people who have already been treated for their cancer. The researchers conducting these trials are hoping to find improved cancer treatments for people with newly diagnosed disease.

- **If you have just found out that you have cancer**, the time to think about joining a trial is before you have any treatment. Talk with your doctor about how quickly you need to make a treatment decision.

Other treatment trials are looking for people who have already been treated for their cancer.

- **If you have already had one or more forms of cancer treatment** and are looking for a new treatment option, there are still clinical trials for you to think about.

## Before You Start

### This section will help you to:

- Understand clinical trials better.
- Find clinical trials that may be a good option for you.

### ➤ Step 1: Understand Clinical Trials

Clinical trials are research studies that involve people. They are the final step in a long process that begins with laboratory research and testing in animals. Many treatments used today are the result of past clinical trials.

If you would like to learn more about clinical trials, or review your understanding of them before going further, the National Cancer Institute (NCI) booklet [Taking Part in Cancer Treatment Research Studies](#) can help you understand what cancer clinical trials are, why they are important, and how they work.

### ➤ Step 2: Talk With Your Doctor

When thinking about clinical trials, **your best starting point is your doctor or another member of your health care team.**

Usually, it is a doctor who may know about a clinical trial, or search for one, that could be a good option for you and your type of cancer. He or she can provide information and answer questions while you think about joining a clinical trial.

In some cases, your doctor may not be taking part in clinical trials or may not be very familiar with them. If your doctor doesn't have information to give you about clinical trials, you may want to get a second opinion about your treatment options and about participating in a clinical trial.

### ▶ **Step 3: Complete the Cancer Details Checklist**

If you decide to look for a clinical trial, **you must know certain details about your cancer diagnosis**. You will need to compare these details with the eligibility criteria of any trial that interests you. Eligibility criteria are the guidelines for who can and cannot take part in a certain clinical trial. They are also called entry criteria or enrollment criteria.

To help you know which trials you may be eligible to join, **complete the Cancer Details Checklist** as much as possible. This form asks questions about your cancer and provides space to write down your answers. Keep the form with you during your search for a clinical trial.

To get the information you need for the form, **ask your doctor, a nurse, or social worker at your doctor's office for help**. Explain to them that you are interested in looking for a clinical trial and that you need these details before starting to look. They may be able to review your medical records and help you fill out the form. The more information you can find to complete the form, the easier it will be to find a clinical trial that might fit your situation.

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## Searching for a Trial

You have learned what clinical trials are and how they work, talked with your doctor about your interest in clinical trials, and prepared a checklist of key details about your cancer. You are now ready to search for clinical trials that might be right for you.

### **This section will help you to:**

- Search the Internet for lists of cancer clinical trials that are accepting eligible people.
- Compare the information on your **Cancer Details Checklist** (from Step 3) with a trial's eligibility criteria and identify trials that might be good options for you.

**Helpful Tip:** *To help tell whether health-related Web sites, including those that*

*list cancer clinical trials, are reliable, see [How To Evaluate Health Information on the Internet: Questions and Answers](#).*

### ▶ **Step 4: Search the U.S. National Cancer Institute's List of Cancer Clinical Trials**

Many Web sites have lists of cancer clinical trials that are taking place in the United States. Some trials are sponsored by non-profit organizations, including the U.S. Federal government, and others are sponsored by for-profit groups, such as drug companies. In addition, there are hospitals and academic medical centers that sponsor trials conducted by their own researchers. Unfortunately, because of the many types of sponsors, no single list of clinical trials is complete.

The National Cancer Institute (NCI), which is part of the U.S. Federal government, has one of the most complete lists of cancer clinical trials available. This list can be searched on NCI's Web site at <http://www.cancer.gov/clinicaltrials/search> on the Internet.

### **How to Search NCI's List of Cancer Clinical Trials**

- 1. Look for trials yourself** using NCI's **clinical trials search form**. A related Web page, **Help Using the NCI Clinical Trials Search Form**, provides more information about how to use the form.

**Helpful Tip:** *Remember to print out or save the clinical trial summary for each trial that interests you.*

- 2. Call NCI's Cancer Information Service (CIS)** at 1-800-4-CANCER (1-800-422-6237). The CIS provides free help in English and Spanish from 8:00 a.m. to 8:00 p.m. Eastern time in the United States. All calls are strictly confidential.
  - **Have your Cancer Details Checklist (from Step 3) handy** when you call the CIS.
  - The CIS is staffed with understanding and knowledgeable **cancer information specialists who will search NCI's list of cancer clinical trials for you**. They can send you the search

results and clinical trial summaries by e-mail, fax, or regular mail. The CIS can also give you reliable information about your type of cancer and the usual treatment for the type of cancer you have.

- If you would like help searching NCI's list of cancer clinical trials while you are on the Internet, **think about using LiveHelp**. Through LiveHelp, you can communicate confidentially and in real time with a CIS information specialist. This service is available Monday through Friday from 8:00 a.m. to 11:00 p.m. Eastern time.

**Helpful Tip:** *The U.S. National Library of Medicine, another Federal agency, manages a Web site called [ClinicalTrials.gov](http://ClinicalTrials.gov), which lists clinical trials for cancer and many other diseases and conditions. The same cancer clinical trials can be found in the NCI and [ClinicalTrials.gov](http://ClinicalTrials.gov) lists. The main difference is in how the information is searched and displayed. You may prefer one list over the other.*

### ▶ Step 5: Search Other Lists of Cancer Clinical Trials

In addition to NCI's list of cancer clinical trials, you may want to check a few other trial lists. Why? Because:

- Some may include a few trials not found in NCI's list.
- You may prefer the way you can search those lists.

Other places to look for lists of cancer clinical trials include the Web sites of:

- Research Organizations that Conduct Cancer Clinical Trials
- Drug and Biotechnology Companies
- Clinical Trial Listing Services
- Cancer Advocacy Groups

**Helpful Tip:** *Whichever Web site you use to search for clinical trials, be sure to get a copy of the clinical trial summary for every trial that interests you.*

*A clinical trial summary should tell you what will*

*be done in the trial, how, and why. It should also list the location(s) where the trial is taking place, so you will know where you have to go to take part in the trial.*

*NCI's list of cancer clinical trials provides a detailed summary for each trial listed. Other non-NCI resources may or may not provide such detailed information about listed trials.*

### Web Sites of Research Organizations that Conduct Cancer Clinical Trials

Many cancer centers across the United States, including NCI-designated Cancer Centers, sponsor or take part in cancer clinical trials. The Web sites of these centers usually have a list of the clinical trials taking place at their location. Some of the trials included in these lists, mainly phase I clinical trials (also called phase 1 trials), may not be in NCI's list.

Keep in mind that the amount of information about clinical trials on these Web sites can vary considerably. You may have to contact a cancer center's clinical trials office to get more information about the trials that interest you. See a list of [NCI-designated Cancer Centers](#).

Another place to look is the [TrialCheck®](#) Web site. This Web site is managed by an organization called the Coalition of Cancer Cooperative Groups (CCCG). The CCCG includes groups of doctors and other health professionals who conduct many of the large cancer clinical trials sponsored by NCI. The TrialCheck Web site has a clinical trials questionnaire that helps you search for trials based on your cancer type and the treatment(s) you have already received. Most of the clinical trials listed on the TrialCheck Web site are the same as those found in NCI's clinical trials list.

### Drug and Biotechnology Company Web Sites

Drug and biotechnology companies also sponsor cancer clinical trials. Many of these trials are included in NCI's list of cancer clinical trials, but some are not.

### How to search for company-sponsored trials:

- Search the U.S. Web sites of drug and biotechnology companies. Many companies provide lists of the clinical trials that they

sponsor on their Web sites. Sometimes, a company's Web site may refer you to the Web site of another organization that helps the company find patients for its trials. The other organization may be paid fees for this service.

The Web site of the Pharmaceutical Research and Manufacturers of America (PhRMA) includes a list of its **member companies**, many of which sponsor cancer clinical trials. PhRMA is a trade organization that represents drug and biotechnology companies in the United States.

- Search the **Clinical Trials Portal of the International Federation of Pharmaceutical Manufacturers & Associations (IFPMA)**. The IFPMA Web portal includes trials found in NCI's list of cancer clinical trials, as well as some other trials. You can search for clinical trials based on cancer type or other medical condition, drug name, and geographic location (for example, the United States).

### Clinical Trial Listing Services

Other organizations provide lists of clinical trials as a major part of their business. These organizations generally do not sponsor or take part in clinical trials. Some of them may receive fees from drug or biotechnology company sponsors of trials for listing their trials or helping them find patients for their trials.

#### Keep the following points in mind:

- The trial lists provided by these organizations often rely heavily on trial lists that are available at no cost from the U.S. Federal government (NCI and ClinicalTrials.gov).
- The trial lists provided by these organizations may have a few more trials than NCI's list, or they may have fewer trials.
- Unlike the NCI Web site (and ClinicalTrials.gov), the Web sites of these organizations may not be updated regularly.
- Unlike the NCI Web site (and ClinicalTrials.gov), the Web sites of these organizations may require you to register to search for clinical trials or obtain trial contact information for trials that

interest you.

Links to the Web sites of several clinical trial listing services are given below. Clicking on the links will help you learn more about the Web sites, what the organizations that manage the sites have to offer, and their clinical trial lists.

- [Acurian.com](http://Acurian.com)
- [BreastCancerTrials.org](http://BreastCancerTrials.org)
- [Cancer411.org](http://Cancer411.org)
- [CenterWatch.com](http://CenterWatch.com)
- [ClinicalTrialsSearch.org](http://ClinicalTrialsSearch.org)
- [eCancerTrials.com](http://eCancerTrials.com)
- [EmergingMed.com](http://EmergingMed.com)

### Cancer Advocacy Group Web sites

Cancer advocacy groups work on behalf of people diagnosed with cancer and their loved ones. They provide education, support, financial assistance, and advocacy to help patients and families who are dealing with cancer, its treatment, and survivorship. These organizations recognize that clinical trials are important to improving cancer care. They work to educate and empower people to find information and obtain access to appropriate treatment.

Advocacy groups work hard to know about the latest advances in cancer research. They will sometimes have information about certain government-sponsored clinical trials, as well as some trials sponsored by cancer centers or drug and biotechnology companies.

#### How to search for trials through a cancer advocacy group:

- Search the Web sites of advocacy groups for specific types of cancer. Many of these Web sites have lists of clinical trials or refer you to the Web sites of organizations that match patients to trials. The CancerActionNow.org Web site, managed by the non-profit Marti Nelson Cancer Foundation, provides a **partial list of cancer advocacy groups**. Or, you can contact an advocacy group directly for assistance in finding clinical trials.

## ➤ Step 6: Make a List of Potential Clinical Trials

At this point, you should have completed the Cancer Details Checklist (in Step 3), found one or more trials of interest to you, and printed out or saved a summary for each trial.

### This section will help you to:

- take a closer look at the trial summaries
- narrow your list to include only those trials for which you would like to get more information

### Key questions to ask about each trial

**Helpful Tip:** *Don't worry if you cannot answer all of the questions below just yet. The idea is to narrow your list of trials, if possible. However, don't give up on trials you're not sure about. You may want to talk with your doctor or another health care team member during this process, especially if you find the trial summaries hard to understand.*

- **Trial objective:** What is the main purpose of the trial? Is it to cure your cancer? To slow its growth or spread? To lessen the severity of cancer symptoms or the side effects of treatment? To determine whether a new treatment is safe and well tolerated? Read this information carefully to learn whether the trial's main objective matches your goals for treatment.
- **Eligibility criteria:** Do the details of your cancer diagnosis and your current overall state of health match the trial's entry criteria? This may tell you whether or not you can qualify for the trial. If you're not sure, keep the trial on your list for now.
- **Trial location:** Is the location of the trial manageable for you? Some trials take place at more than one location. Look carefully at how often you will need to receive treatment during the course of the trial. Decide how far and how often you are willing to travel. You will also need to ask whether the sponsoring organization will pay for some or all of your travel costs.
- **Study length:** How long will the trial run? Not all clinical trial summaries provide this information.

If they do, consider the time involved and whether it will work for you and your family.

After considering these questions, if you are still interested in one or more of the clinical trials you have found, then you are ready for Step 7.

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## After Finding a Trial

Now that you have found clinical trials for which you may be eligible and that interest you, it's time to make a phone call to each trial's contact person or central office so you can ask a few more important questions. Once you have gathered all the information you can, you will be ready to make a final decision.

## ➤ Step 7: Contact the Clinical Trial Team

There are many ways to contact the clinical trial team.

- **Contact the trial team directly.** The clinical trial summary should include the phone number of a person or an office that you can contact for more information. You do not need to talk to the lead researcher (called the "protocol chair" or "principal investigator") at this time, even if his or her name is given along with the telephone number. Instead, call the number and ask to speak with the "trial coordinator," the "referral coordinator," or the "protocol assistant." This person can answer questions from patients and their doctors. It is also this person's job to decide whether you are likely to be eligible to join the trial. (A final decision will probably not be made until you have had a visit with a doctor who is taking part in the trial.)
- **Ask your doctor or another health care team member to contact the trial team for you.** Because the clinical trial coordinator will ask questions about your cancer diagnosis and your current general health, you may want to ask your

doctor or someone else on your health care team to contact the clinical trial team for you.

- **The trial team may contact you.** If you have used the Web site of a clinical trial listing service and found a trial that interests you, you may have provided your name, phone number, and e-mail address so the clinical trial team can contact you directly.

You will need to refer to your **Cancer Details Checklist** (from Step 3) during this conversation, so keep it handy.

### **▶ Step 8: Ask Questions About the Trial**

Whether you or someone from your health care team calls the clinical trial team, this is the time to get answers to questions that will help you decide whether or not to take part in this particular clinical trial.

It will be helpful if you can talk about your cancer and your current general health in a manner that is brief and to the point. Before you make the call, you may want to rehearse how you will present key information about your cancer diagnosis and general health with a family member or a friend. This will make you more comfortable when you are talking with the clinical trial team member, and it will help you answer his or her questions more smoothly.

**Remember to keep your Cancer Details Checklist (from Step 3) handy** to help you answer some of the questions that may be asked.

**1. Is the trial still accepting people?** On occasion, clinical trial listings will be out of date and will include trials that are no longer accepting new participants.

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**2. Am I eligible for this trial?** The trial team member will ask you many, if not all, of the questions listed on your Cancer Details Checklist (from Step 3). This is the time to confirm that you are a candidate for this trial. However, a final decision will likely not be made

until you have had your first visit with a doctor who is taking part in the clinical trial (Step 10).

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**3. Why do researchers think the new treatment might be effective?** Results from previous research have indicated that the new treatment may be effective in people with your type of cancer. Ask about the previous research studies. Results from studies in humans are stronger than results from laboratory or animal studies.

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**4. What are the potential risks and benefits associated with the treatments I may receive in this trial?** Every treatment has risks, whether you receive the treatment as part of a clinical trial or from your doctor outside of a clinical trial. Be sure you understand the possible risks and side effects of each treatment you may receive as a participant in this trial. Also, ask for a detailed description of how the treatments you may receive could benefit you.

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**5. Who will watch over my care and safety?** Primary responsibility for the care and safety of people taking part in a cancer clinical trial rests with the clinical trial team. Also, clinical trials are governed by safety and ethical regulations set by the Federal government and the organization sponsoring and carrying out the trial. One of these groups is called the

Institutional Review Board (IRB). The trial team will be able to give you more information. You can also see [Protecting Participants in Clinical Trials](#).

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**6. Can I get a copy of the trial’s protocol document?** A trial’s protocol document is an action plan for the trial. It includes the reason(s) for doing the trial, the number of people that will be included, the eligibility criteria for participation, the treatments that will be given, the medical tests that will be done and how often, and what information will be collected. These documents are usually written in highly technical language and are often confidential. In some cases, however, the trial team may be allowed to release the protocol document to you.

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**7. Can I get a copy of the informed consent document?** Yes. The U.S. Food and Drug Administration (FDA) and the Office for Human Research Protections (OHRP) require that potential participants in a clinical trial receive detailed, understandable information about the trial. This process is known as “informed consent,” and it must be in writing. It may be helpful to see a copy of this document before you make your final decision about joining the trial. For more information about informed consent, see [A Guide to Understanding Informed Consent](#).

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**8. Is there a chance that I will receive a placebo?** Placebos (sham or inactive treatments) are rarely used alone in cancer treatment trials. When they are used, they are most often given along with a standard (usual) treatment. In such cases, a trial will compare a standard treatment plus a new treatment with the

same standard treatment plus a placebo. If a placebo is used alone, it’s because no standard treatment exists. In this case, a trial will compare the effects of a new treatment with the effects of a placebo. Be sure you understand the treatments that are being used in any trial you are thinking of joining

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**9. Is the trial randomized?** In a randomized clinical trial, participants are assigned by chance to different treatment groups or “arms” of the trial. Neither you nor your doctor can choose which arm you are in. All participants in an arm receive the same treatment. At the end of the trial, the results from the different treatment arms are compared. In a randomized trial, you may or may not receive the new treatment that is being tested. (See [What Is Randomization?](#)).

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**10. What is the dose and schedule of the treatments given in each arm of the trial?** Dose refers to the amount of treatment given, and schedule refers to when and how often treatment is given. You will want to think about this information when you are discussing your treatment options with your health care team. Is the treatment schedule manageable for you?

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**11. What costs will I or my health insurance plan have to pay?** In many cases, the research costs are paid by the organization sponsoring the trial. Research costs include the treatments being studied and any tests performed purely for research



purposes. However, you or your insurance plan would be responsible for paying “routine patient care costs.” These are the costs of medical care (for example, doctor visits, hospital stays, x-rays) that you would receive whether or not you were taking part in a clinical trial. Some insurance plans don’t cover these costs once you join a trial. Consult your health plan, if you have one, or go to [States That Require Health Plans to Cover Patient Care Costs in Clinical Trials](#) to see if your plan must provide such coverage. You may also wish to consult [Clinical Trials and Insurance Coverage - A Resource Guide](#).

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**12. If I have to travel, who will pay for my travel and lodging?** Clinical trials rarely cover travel and lodging expenses. Usually, you will be responsible for these costs. However, you should still ask this question.

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**13. Will participation in this trial require more time (hours/days) than standard care? Will participation require a hospital stay?** Understanding how much time is involved and whether a hospital stay is required, compared to the usual treatment for your type of cancer, may influence your decision. This information will also be important if you decide to take part in the trial because it will help you in making plans.

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**14. How will participating in this trial affect my everyday life?** A diagnosis of cancer can disrupt the routine of your everyday life. Many people seek to keep their routine intact as they deal with their cancer and its treatment. This information will be useful in making plans and in determining whether you need any additional help at home.

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**➤ Step 9: Discuss Your Options With Your Doctor**

To make a final decision, you will want to know the potential risks and benefits of all treatment options available to you. Through the research that you have done, you likely have a good idea about the possible risks and benefits of the treatment(s) in clinical trials that interest you. If you have any remaining questions or concerns, you should discuss them with your doctor. You should also ask your doctor about the risks and benefits of standard, or usual, treatment for your type of cancer. Then, you and your doctor can compare the risks and benefits of standard treatment with those of treatment in a clinical trial. You may decide that joining a trial is your best option, or you may decide not to join a trial. It’s your choice.

For more information, see [Participating in a Trial: Questions to Ask Your Doctor](#).

**➤ Step 10: If You Want to Join a Trial, Schedule a Visit**

If you decide to join a clinical trial for which you are eligible, schedule a visit with the trial team (most likely, the same person you spoke with in Step 8).

## Cancer Details Checklist

Fill out this Cancer Details Checklist as completely as possible before you start looking for a clinical trial. It will help you know which clinical trials you may be eligible to join.

See **Step 3** for information about how to obtain the details you need for the checklist.

### 1. What kind of cancer do you have?

Write down the full medical name.

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### 2. Where did the cancer first start?

Many cancers spread to the bones, liver, or elsewhere. However, the type of cancer you have is determined by where it started. For example, breast cancer that spreads to the bone is still breast cancer.

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### 3. What is the cancer's cell type?

This information will be in your pathology report.

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### 4. If you have a solid tumor, what size is it?

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### 5. If you have a solid tumor, where is it located?

If the tumor has spread, list all locations.

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### 6. What is the stage of your cancer?

The stage describes the extent of cancer in the body and whether it has spread from the site where it started. There are different staging systems for different cancers.

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### 7. Have you had cancer before that is different from the one you have now? If so, answer questions 1-6 for the other cancer, as well.

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**8. What is your current performance status score?**

This is an assessment by your doctor of how well you are able to perform ordinary tasks and carry out daily activities. Several different scoring methods can be used to describe performance status.

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**9. Have you been treated for your current cancer? If not, what treatment(s) have been recommended to you?**

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**10. If you have been treated for your current cancer, please list the treatments you have received (for example: type of surgery, chemotherapy, immunotherapy, or radiation therapy).**

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**11. What are your bone marrow function test results?** These blood tests show whether your blood cell count is normal.

a) **White blood cell count:**

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b) **Platelet count:**

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c) **Hemoglobin/hematocrit:**

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**12. What are your renal function test results?**

a) **Bilirubin:**

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b) **Transaminases:**

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**13. What are your renal function test results?**

This blood test checks whether your kidneys are functioning normally.

a) **Serum creatinine**

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## Who Produced This Guide?

This original version of this guide was produced collaboratively by:

- The **U.S. National Cancer Institute (NCI)**: The U.S. Federal government's chief cancer research agency, part of the U.S. National Institutes of Health, and a component the U.S. Department of Health and Human Services
- The **U.S. Food and Drug Administration**: The agency in the U.S. Department of Health and Human Services that is charged with ensuring the safety and effectiveness of new drugs and medical products
- The Summit Series on Cancer Clinical Trials: A multi-year effort involving health care providers from academic and community cancer centers, representatives of patient advocacy organizations, and others involved in the U.S. cancer clinical trial system that focused on improving awareness and understanding of cancer clinical trials and on increasing the percentage of patients who participate in cancer clinical trials.

The current version of the guide was revised and updated by NCI staff.

### For More Information

Visit the NCI Web site at  
<http://www.cancer.gov/clinicaltrials>.

or call the NCI's Cancer Information Service  
at 1-800-4-CANCER