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http://www.cancer.net/cancer-types/retinoblastoma-childhood/about-clinical-trials

Retinoblastoma - Childhood - About Clinical Trials [1]

This section has been reviewed and approved by the Cancer.Net Editorial Board [2], 08/2015

ON THIS PAGE: You will learn more about clinical trials, which are the main way that new medical approaches are tested to see how well they work. To see other pages, use the menu on the side of your screen.

What are clinical trials?

Doctors and scientists are always looking for better ways to care for children with retinoblastoma. To make scientific advances, doctors create research studies involving volunteers, called clinical trials. In fact, every drug that is now approved by the U.S. Food and Drug Administration (FDA) was previously tested in clinical trials.

Many clinical trials are focused on new treatments, evaluating whether a new treatment is safe, effective, and possibly better than the current (standard) treatment. These types of studies evaluate new drugs, different combinations of existing treatments, new approaches to radiation therapy or surgery, and new methods of treatment. Children who participate in clinical trials are among the first to receive new treatments before they are widely available. However, there is no guarantee that the new treatment will be safe, effective, or better than a standard treatment.

There are also clinical trials that study new ways to ease symptoms and side effects during treatment and managing the late effects that may occur after treatment. Talk with your doctor about clinical trials regarding side effects. In addition, there are ongoing studies about ways to prevent the disease.

Deciding to join a clinical trial

Patients decide to participate in clinical trials for many reasons. For some patients, a clinical trial is the best treatment option available. Because standard treatments are not perfect, patients are often willing to face the added uncertainty of a clinical trial in the hope of a better result. Other patients volunteer for clinical trials because they know that these studies are the only way to make progress in treating retinoblastoma. Even if they do not benefit directly from the clinical trial, their participation may benefit future patients with retinoblastoma.

Sometimes people have concerns that, in a clinical trial, their child may receive no treatment by being given a placebo or a "sugar pill." The use of placebos in cancer clinical trials in this way is rare overall and not done at all in childhood cancer research. Find out more about placebos in cancer clinical trials. [3]

[4]Patient safety and informed consent

To join a clinical trial, parents and children must participate in a process known as informed consent. During informed consent, the doctor should list all of the patient's options, so that the person understands how the new treatment differs from the standard treatment. The doctor must also list all of the risks of the new treatment, which may or may not be different from the risks of standard treatment. Finally, the doctor must explain what will be required of each patient in order to participate in the clinical trial, including the number of doctor visits, tests, and the schedule of treatment.

Children who participate in a clinical trial may stop participating at any time for any personal or medical reason. This may include that the new treatment is not working or there are serious side effects. Clinical trials are also closely monitored by experts who watch for any problems with each study. It is important that parents with a child participating in a clinical trial talk with their child's doctor and researchers about who will be providing their treatment and care during the clinical trial, after the clinical trial ends, and/or if the child leaves the clinical trial before it ends.

Finding a clinical trial

Research through clinical trials is ongoing for all types of cancer. For specific topics being studied for retinoblastoma, learn more in the Latest Research [5] section.

Cancer.Net offers a lot of information about cancer clinical trials in other areas of the website, including a complete section on clinical trials [6] and places to search for clinical trials for a specific type of cancer [7].

In addition, this website offers free access to a video-based educational program [8] about cancer clinical trials, located outside of this guide.

The next section in this guide is Latest Research [5] *and it explains areas of scientific research currently going on for this type of cancer. Or, use the menu on the side of your screen to choose*

another section to continue reading this guide.

Links
[1] http://www.cancer.net/cancer-types/retinoblastoma-childhood/about-clinical-trials
[2] http://www.cancer.net/about-us
[3] http://www.cancer.net/node/24390
[4] http://www.cancer.net/navigating-cancer-care/how-cancer-treated/clinical-trials/placebos-cancer-clinical-trials
[5] http://www.cancer.net/node/19587
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