In My Community

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A Clinical Trial Could Save Your Life

One Man's Story of Survival

In 2002, after three stem cell transplants had provided a decade of remissions, Jim Bond of Shaker Heights, Ohio, was running out of options. His multiple myeloma, a cancer of bone marrow plasma cells, was raging out of control, and Jim knew he was facing death. That's when he and his wife Kathleen asked his doctor about a new drug they had learned was showing promising results in early clinical trials.

With persistence, Jim located and began a clinical trial in Boston for the drug then known as PS341. Within weeks of his first treatment cycle, Jim's cancer level dropped 99% and provided him another remission for a cancer that historically has a three- to five-year survival rate.

"It turned our world around completely," said Kathleen.

Further testing proved PS341, now called Velcade, showed great promise among others very sick like Jim, and it received the fastest FDA approval of any cancer medication.

If Jim had relied on what was then standard treatment, he might not have survived. Instead, his participation in a clinical trial allowed him to be among the first to benefit from a lifesaving new treatment.

"Kathleen and I were confident this clinical trial was our best hope, and we know that without it, I would not be here today," Jim said.

Cancer patients and caregivers may not realize that alternative options afforded by clinical trials are available to them. A clinical trial could save your life. Read on to find out more.

What Are Clinical Trials?

Clinical trials are research studies involving people. They start only after a new treatment has been carefully studied in the laboratory. Clinical trials try to answer specific questions about new and better ways to help prevent, diagnose, or treat diseases.

Some, like the one Jim Bond participated in, study new anticancer drugs, while others look at new ways to use current drugs or other forms of treatment.

Most of today's treatments for cancer are based on the results of earlier clinical trials.

"Jim is a big believer in clinical trials. He knew the drug might not work. But at least he felt it was important to contribute to the body of knowledge about this drug," Kathleen said.

Now a 13-year cancer survivor, Jim is currently enrolled in another clinical trial for a drug called Revlimid to maintain his remission. He works full-time and enjoys a normal, active life, as he has done throughout his battle with cancer. He and Kathleen view his illness as a manageable, chronic disease for which there is no cure, yet.

Clinical Trials Are Underused

Hundreds of clinical trials are currently taking place at institutions across the United States, yet only 3% of US adults with cancer participate in clinical trials.

Many patients simply don't know about clinical trials or don't have access to them. Other times they may be afraid or suspicious of research.

History is to blame for some of this distrust. In the infamous Tuskegee experiment of 1932-1972, doctors did not treat about 400 African Americans infected with syphilis so they could determine if the disease affected blacks differently from whites.

Today, federal regulations ensure that people are told about the benefits, risks, and purpose of research before they agree to participate. Patients' rights are also protected through scientific review, institutional review boards, and data safety and monitoring boards.

Despite any possible risks, participants in clinical trials receive excellent care.

"I found that doctors and nurses paid close attention to my test results, side effects, and my questions when in a clinical trial. Rather than being treated like a guinea pig, I was treated with compassion and empathy," Jim said. "At all times, I felt that the medical professionals placed my well-being ahead of clinical trial protocols."

Another barrier to participation in clinical trials is the misperception that patients may be given placebos. However, placebos are almost never used in cancer clinical trials. They are used only when no standard treatment already exists, and patients are told of this possibility before deciding to take part.

In addition to fears and misperceptions regarding clinical trials, some patients may be reluctant to seek help beyond their local doctor.

"Some patients hesitate to leave their local oncologist for an out-of-town comprehensive cancer center that treats more cases of their type of cancer. I encourage others to consider doing this when circumstances permit," Jim said. "We have found that local oncologists can work cooperatively with doctors from major cancer centers, and the big winner is the patient. Our advice is to not hesitate to raise this possibility to your local doctor."

Of course, people choose to enter clinical trials for different reasons. Clinical trials have both benefits and risks; they are not the right option for everyone. *See box "Benefits and Risks" below.*

"Kathleen and I both hope that in the future, many more patients will consider entering clinical trials - both to help themselves, and to move us closer to a cure," Jim said.

Benefits and Risks

Possible Benefits of Participating in a Clinical Trial

- Participants will receive, at a minimum, the best standard treatment
- If the new treatment or intervention is proven to work, participants may be among the first to benefit.
- Participants have a chance to help others and improve cancer care.

Possible Risks of Participating in a Clinical Trial

- New approaches may have side effects or risks that are unknown.
- Even if a new treatment under study has benefits, it may not work for every participant. (If this is the case, your doctor will remove you from the trial and suggest another treatment option.)
- Participants may have to pay for the costs of travel, childcare, lost work hours, and meals. (Some trials do reimburse patients for some of these costs.)

How Can a Patient Find Out About Clinical Trials?

Cancer patients can find free information about clinical trials 24 hours a day, seven days a week by using the American Cancer Society Clinical Trials Matching Service. This service can also be accessed by calling 1-800-303-5691.

While other clinical trials information services exist, the Society's is the most comprehensive and is unique in that it narrows the search for the patient. Other services require the patient to manually sort through a list of trials and eligibility information in order to determine which trials are relevant to their diagnosis. The Society's service makes the process easier and quicker for the patient.

Patients who access the Clinical Trials Matching Service learn about clinical trials for which they might be eligible based on their specific cancer diagnosis. After completing the questionnaire, they receive a summary of the clinical trials, as well as contact information for the study coordinators. People can also learn about prevention and early detection clinical trials in which they might be able to participate.

"There is no substitute for learning about clinical trials available for your cancer," Jim said. "The American Cancer Society's clinical trials matching service is an excellent resource."

More information on clinical trials is available on this Web site or call 800-ACS-2345.

Additional Resources

Nurses and other health care professionals may find out more about clinical trials by accessing the Clinical Trials Education Series (CTES) available on the National Cancer Institute Web site at www.cancer.gov.

These resources can be downloaded or ordered online or by telephone. CTES includes free workbooks, booklets, brochures, videos, and slide presentations. They include materials appropriate for a range of audiences, such as brochures geared to low-literacy English-speaking patients and Spanish-speaking patients, as well as in-depth resources to educate health care workers.