Clinical Trials Matter: What Our Patients Say

From brain cancer to sarcoma, Fred Hutch patients tout access to innovations, longer survival and the opportunity to help shape cancer care.

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A clinical trial is a research study involving a select group of people — either healthy individuals or patients dealing with a disease — who have volunteered to try a new intervention under close medical monitoring.

Clinical trials are crucial for people dealing with cancer, propelling new treatment options and potential cures forward.

Once completed, clinical trials — which are organized into four different phases — answer researchers' questions about the safety and/or effectiveness of the intervention, such as a new drug, therapy or technology that may save future lives.

Fred Hutch Cancer Center has been running clinical trials to provide better outcomes for patients since its founding. Our physicians know how important these trials are for moving treatment improvements forward.

"Clinical trials are vital to develop new and improved treatments for patients, especially those who have conditions where current treatments don't have the best outcomes," said radiation oncologist Lia Halasz, MD, who treats brain and central nervous system cancers at Fred Hutch - Proton Therapy. "Clinical trials have led to the great innovations in oncology that we've seen at Fred Hutch over the past decades."

Yolanda Tseng, MD, MPhil, who leads the clinical trials program for the Radiation Oncology Division at Fred Hutch and the University of Washington, stressed the importance of trials for reducing the toxicity of cancer treatment.

"Clinical trials are the gold standard for us to understand how best to screen, treat and/or follow patients with cancer," she said. "We want to be able to continually improve outcomes and reduce any negative effects from treatment to the patient."

"There are also immediate benefits of participating in clinical trials," said Fred Hutch - Proton

Therapy Medical Director Annemarie Shepherd, MD. "Patients can benefit from closer medical monitoring and early complication detection, and studies have found that patients who participate in clinical trials tend to have better outcomes than patients who do not."

Why do patients participate in clinical trials?

Proton therapy patients routinely participate in clinical trials for a variety of cancers. We reached out to get their take on why they chose to join a trial, what the trial experience was like and what they would recommend for people considering a clinical trial.

Ethan Wheeler enrolled in a clinical trial for brain cancer at age 16, believing he had nothing to lose by participating. Wheeler's trial tested whether a lower dose of radiation would be as effective as the proven, higher doses while reducing short- and long-term side effects. As is always the case before a clinical trial enrolls patients, non-human trials had already shown that this was likely true.

"If I could help other kids have easier treatments, I thought I might as well do it," he said.

His mother, Jessica Wheeler, had more nuanced feelings.

"I couldn't help worry that the lower dose might not be as effective," she said. "Ethan's doctors had recommended the trial because a lower dose of radiation — delivered via proton therapy — would have fewer negative side effects on his still-developing brain."

While worrisome, his mother agreed it was a good option to try.

Jane Cho, a Fred Hutch employee and sarcoma patient for the past 16 years, had proton therapy for a previous recurrence. She had similar feelings of uncertainty when she enrolled in a clinical trial to treat a third recurrence last year.

"I was nervous but hopeful," she said. "I was patient number two of 10 open spots. I felt like I had won the lottery, but I was nervous because there was a risk that this new treatment type wouldn't be effective. At a third recurrence, my treatment options were starting to be limited. It also felt good to be part of something that could become an approved treatment for others with the same disease."

Gillian McDonald, 33, was diagnosed with rare triple negative stage 3c inflammatory breast cancer after noticing a lump during a breast self-exam.

After learning she had an aggressive type of breast cancer that had already spread to lymph nodes, McDonald decided to participate in several clinical trials, including a proton therapy trial, hoping to find a cure. More than two years post-treatment, she's doing well.

"I think it's very important to take part in clinical trials and to be part of the research that may lead to a cure," she said. "This is how we move medicine forward. For me, it's been an amazing

experience.”

Bob Duncan, who enrolled in a skin cancer clinical trial, also pointed to the importance of advancing treatment options as a reason to participate. Diagnosed with squamous cell carcinoma that grew along the nerves in his face, his trial tested whether combining a type of immunotherapy drug called a checkpoint inhibitor before and after (proton) radiation therapy would enhance doctors’ ability to treat inoperable cancers like his. Currently, all his scans look clear.

Options used to be limited, but now there are so many,” he said. “It shows we’re successful in treating cancer.”

Sadly, not all patients with cancer are able to survive the disease, although many are able to extend their lives through clinical trials.

One such patient, Liz Kuper, MD, was a Boise, Idaho-based family physician whose metastatic breast cancer advanced to leptomeningeal disease (LMD) earlier this year. In LMD, tumor cells float freely in the cerebrospinal fluid that bathes the brain and spinal cord; it remains a serious complication of metastatic cancer associated with poor prognosis and limited treatment options.

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