



# Patient Perspective

*The stories below are from a series of articles created by CISCRP as part of their educational awareness campaign to increase public understanding that those who volunteer to participate in clinical trials are genuine “Medical Heroes.”*

## **Alexandra Scott**

Alexandra “Alex” Scott was an upbeat, spirited little girl who developed cancer before her first birthday. Three years later, after receiving intensive chemotherapy and stem cell treatments, Alex asked her parents if she could set up a lemonade stand by their house in Manchester, CT.

“We kind of laughed,” says her father, Jay Scott. “We thought she was going to use the money to buy a toy.” But Alex surprised everyone. Her lemonade stand raised \$2,000, which she donated to “her” doctors. “All kids want their tumors to go away,” Alex explained.

Alex’s cancer treatments began when she developed neuroblastoma as a baby. Doctors removed most of her tumor, but more grew back. Over the next three years, Alex had chemotherapy and more surgery. When the chemotherapy no longer worked, parents Liz and Jay Scott brought Alex to the Children’s Hospital of Philadelphia for experimental treatments.

“We were told by several hospitals that there were no more treatment options and we should just enjoy her last days,” says Jay. “But the experimental treatments gave her 4-1/2 more years with us.”

“We were reassured that the doctors gave Alex very thorough checkups before she received treatment, to see if she was a good candidate,” adds Liz.

Sunny little Alex braved through continued experimental treatments. Despite their heartbreak, Liz, Jay, and Alex’s brothers stayed upbeat and positive for her. “Any strength and heroism we may have shown was coming from Alex, and seeing how she dealt with things,” says Liz.

Alex died at age 8 from her cancer, at home with her family. Her parents credit the experimental treatment with giving her more time to enjoy herself and raise money to help other children with cancer.

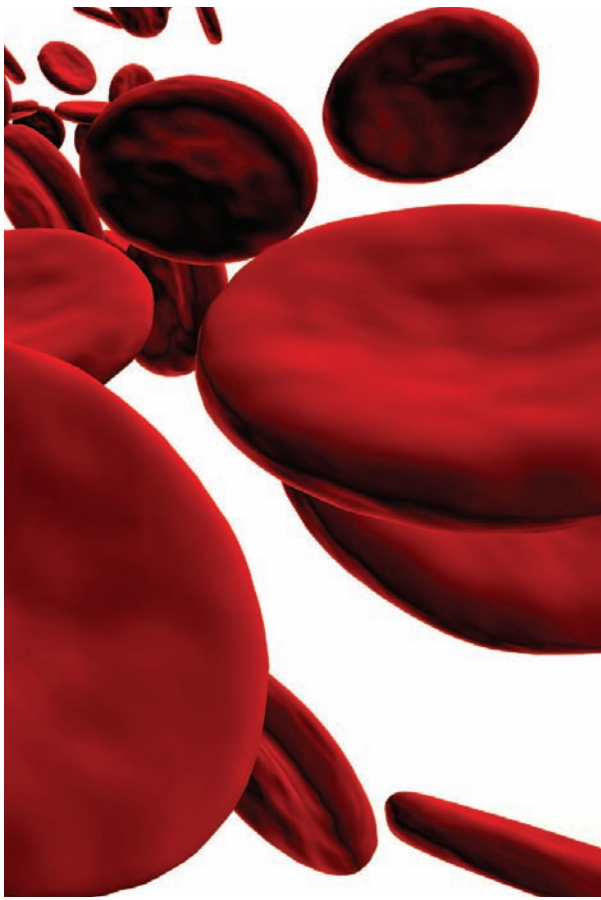
“Experimental treatment is a different decision for every parent,” says Liz.

“In the back of your mind you’re always hoping for a cure.”

## **Brennen Teel**

Just hours after her son, Brennen, 6, was diagnosed with acute lymphocytic leukemia, Becky Teel made a decision that would change their lives forever. Teel opted to enroll her son in an experimental study that would pit his illness against the same powerful drugs as conventional chemotherapy, but use them in different sequences and combinations.

Believing the regimen would give Brennen his best shot at beating the disease, Teel pushed her son to persevere through rounds of treatment and days of vomiting that followed. Three years later, with Brennen in remission, Teel signed him up for a second study on the effects of cancer treatment on children’s growth. Now 27 years old and a six-foot Texas Tech undergraduate, Brennen continues to allow researchers to track the growth of his body, mind, and spirit.



Like thousands of others each year, Becky Teel showed support for clinical research by enrolling her child in a clinical trial. The decision helped Teel unleash a powerful ally in the battle against Brennen's illness, and made her a believer in the importance of clinical research.

"The comfort I got from working with a team of people who were sympathetic, empathetic and driven to help was enormous," recalls Teel. "They were like another family to me, and they put us at the cutting edge of research."

#### **Jean Burns**

Jean Burns of Arizona enrolled in a Phase II/III clinical trial shortly after being diagnosed with Parkinson's disease at the age of 51. The graphic designer and former software trainer hoped the experimental drug CEP-1347 would stop the progression of her disease and put her at the forefront of treatment. It didn't happen that way.

Two years after Burns enrolled, the study was halted because CEP-1347 didn't work. Despite her disappointment, Burns continues to speak out on clinical research's

potential for creating a brighter future.

"If the drug had worked, it would have helped me and other people," Burns relates. "Less than one percent of people with Parkinson's disease participate in clinical trials, but if nobody does it, we'll never succeed. I really hoped it would work."

#### **John Cleland**

John Cleland of Indianapolis has run four marathons, but the race he is proudest to have won was against testicular cancer. Diagnosed in 1973 at 22 years of age, Cleland, then a newly married, Purdue University undergraduate, underwent surgical removal of his testicle and 53 lymph nodes. Three punishing rounds of chemotherapy followed. But when Cleland's cancer spread to his lungs, the optimism that had buoyed the Indiana native through nearly a year of treatment began to wane. He wondered what the future would hold.

"At that point I weighed 105 pounds, I had no hair on my body, and the sores in my mouth were so bad I couldn't swallow," Cleland recalls. "My doctor, Dr. Lawrence Einhorn, called me into his office and said, 'John, I don't think you're going to make it. I don't think you're going to survive.'" Mind racing, heart pounding, Cleland tried to focus as Einhorn offered one last option.

"He said, 'There is one other thing we can try,'" Cleland recalls. " 'You can be one of the very first people to try a new chemotherapy.'" Even though Cleland had studied science in college, he knew nothing about clinical research, and today, the 58-year-old teacher admits if you'd asked him at the time what a clinical trial was, he wouldn't have been able to answer. What Cleland did know, however, was that the experimental

treatment Einhorn was proposing held a chance for survival so he grabbed it.

"I knew I could die or I could do something else," Cleland says. "After thinking for five or ten minutes about what I could expect, I decided I didn't have anything to lose."

On October 7, 1974, Cleland began receiving daily injections of the experimental drug, cisplatin. With just two other people enrolled in the trial before him, Cleland did not know what to expect. When he developed a severe reaction to the treatment just two weeks later, neither he nor Einhorn was surprised.

"I'd already been beaten pretty badly and it was more of the same in a lot of ways," the high school biology teacher and cross-country coach recalls. Severe vomiting, high fever, and painful mouth and throat sores had plagued Cleland throughout his cancer treatments. But this time there was one big difference. Cleland's lungs were clear. The radiologist who read his chest x-ray was so stunned, he had to verify he'd read the right person's film. When Einhorn arrived to give his patient the news, he smiled broadly and said, 'John, we think you're going to make it.' "

That was more than 30 years ago, and since that time, Cleland has lived a remarkably healthy, happy life. He and his wife, Judy, have three children, and in 2002, the former competitive runner proudly carried the Olympic torch through the streets of Indianapolis. The experimental drug, cisplatin, is now a formidable weapon in the fight against many forms of cancer

#### **Barbara Holtz**

Editor. Teacher. Marketing professional. Barbara Holtz has had

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a varied career. Perhaps her most meaningful “job” was as a clinical research participant. Diagnosed with invasive ductal carcinoma in 2001, Holtz underwent a lumpectomy and axillary node dissection and entered the Dana-Farber Cancer Institute for treatment soon after. At their very first meeting, her oncologists suggested she consider enrolling in a clinical trial of the drug Herceptin. “Up to that point, Herceptin had been widely used to treat metastatic breast cancer,” Holtz recalls. “This important, national trial was to test whether Herceptin could be effective and nontoxic to early-stage patients and possibly prevent their cancers from progressing.”

Eager to launch an all-out attack on her disease, Holtz took a “leap of faith” and agreed to participate. It was not an easy choice. Family members tried to dissuade her, arguing that she’d be better off

staying with “the tried and true” treatment. But Holtz felt otherwise, and clung to her belief that clinical trial subjects contribute to the cause of scientific research – whether or not the experimental drug benefits them in the near term.

“I felt very threatened by this disease, and I wanted to take aggressive steps to fight it,” she recalls. In addition, since the study was a Phase III clinical trial, Holtz knew the drug was “almost ready for prime time.” In the end, her decision turned out to be fortuitous because the regimen she received included both the standard and experimental treatments.

Now a Dana-Farber patient advocate and peer counselor, Holtz says having cancer was terrifying but participating in a clinical trial made her feel she was “doing something about it.” “I had complete faith that

this was the right step,” she says. The intensive monitoring she received throughout her treatment also proved comforting as she battled various side effects.

Holtz’s unstinting support for clinical research was rewarded when the Herceptin trial was halted because the study results proved overwhelmingly positive, and it was decided that eligible patients deserved to receive its benefits early in treatment. “Herceptin – also known as a targeted, biologic therapy – was shutting down a lot of the tumor proliferation so it was made widely available,” she explains.

“I’m glad I did it. The whole thing was a positive experience for me,” Holtz says. “My message to others would be, have an open mind to being a clinical trial subject. Learn all you can about the trial’s purpose and requirements and go for it!” ■

The Center for Information and Study on Clinical Research Participation (CISCRP) is an independent national nonprofit association dedicated to educating and inform-ing the public about clinical trials and research. Working with representatives of every clinical research stakeholder, these CISCRP educational outreach programs include the free eNewsletter *The CISCRP Participant*, and a public service campaign designed to increase the understanding that those who volunteer to participate in clinical trials are genuine “Medical Heroes.”

“The ‘Medical Heroes’ campaign is designed to re-brand the clinical research industry,” explains Diane Simmons, CISCRP President and CEO. “We’re very clear on the level of public distrust in the clinical research enterprise – a really high level of distrust.”

“CISCRP has relationships with a lot of people across the United States who are real medical heroes, real clinical research volunteers. They have been spokepeople at our AWARE-for-All Clinical Research Education Days public education programs,” explains Ken Getz, CISCRP Founder and Board Chair. “We realized how wonderfully the public responds to hearing the real-life stories of folks who have been through trials, and

they share their experiences, explaining both the risks and the benefits to them. By that level of truthfulness and direct communication with the public, we really influence public perception and people start to refer to these folks with great respect.”

CISCRP also offers the “google of clinical trials” search engine, SearchClinicalTrials.org. This allows interested individuals to identify their therapeutic area or disease condition, zip code, and how far they are willing to travel to participate in an appropriate clinical trial; the engine combs all public clinical trial registries and organizes search results by these criteria. Sometimes, CISCRP even connects these individuals to someone working where the study is being conducted, to help them understand the study and nature of their potential participation.

“We’ve seen the bravery and kindness of these regular people who have taken part in clinical trials,” Diane concludes, “and our newsletter is really to honor them and celebrate their spirit.”

If you’d like to receive the free *CISCRP Participant* newsletter, please contact [info@ciscrp.org](mailto:info@ciscrp.org) or call 781-326-3400 (US).