



Patient Perspective



The story below is 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."

Clinical Trials Patients Fight to Conquer Their Disease

Jenna Korb: Back from the Brink

Happy thoughts of a promising future can vanish in an instant.

That's what Jenna Korb, then a bright, lively college student from Montana, learned when she went to the school nurse one day for a check-up.

In 1993, then-19-year-old Jenna had been feeling exhausted and lightheaded. She decided to drop by the college nurse for a spur-of-the-moment checkup.

"I thought I'd get a quick slap on the hand for not getting more sleep and not eating better," says Jenna.

But the nurse told her she looked terrible. "When she pricked my finger for a drop of blood, it didn't even look normal," says Jenna. "It had a consistency like Kool-Aid; it was very clear."

Jenna was rushed to the local hospital. The doctors, who had little experience with blood cancer, initially misdiagnosed her with aplastic anemia, a condition in which the body stops producing enough red blood cells.

"They basically sent my parents home and said they should get my affairs in order," recalls Jenna, who at age 35 is executive director for the

Leukemia & Lymphoma Society San Diego/Hawaii chapter.

Jenna transferred to the Fred Hutchinson Cancer Research Center in Seattle. There she was diagnosed with myelodysplastic syndrome, in which blood cells that develop in the bone marrow are defective and die off.

The prognosis was dire. Jenna began undergoing chemotherapy, but she needed a bone marrow transplant to survive. Her time to find a compatible donor was limited, even though she was getting weekly blood transfusions.

“They told me I had six months to find a match; it took me four months, which was pretty good,” says Jenna.

Jenna’s family moved to Seattle for the treatment period. “It was devastating,” says Jenna. “You lose the whole support group you have at home. We’re from Montana and hadn’t done much traveling yet, so here we were in the big city life, and the whole experience was overwhelming.

“One of the most devastating things was to lose my hair and looking so sick,” Jenna recalls. “I didn’t get a wig; I got great at tying scarves.”

No Time to Think About Her Decision

As she was getting ready to undergo the bone marrow transplant, doctors approached Jenna about taking part in clinical trials.

“I don’t think I ever even heard the phrase mentioned before they prepped me for the transplant,” says Jenna. “They walked in with a very thick stack of paperwork. They said, ‘Here are your options, you pick one or two.’ And that was it.”

“I was not very mentally capable at that time. You look at those medical documents and you have no idea what they mean. There wasn’t anyone to sit with us and read through them with us and make recommendations.”

“My mom had power of attorney at the time. But I didn’t let my mom make the decision because I didn’t want her to feel responsible.”

Jenna decided to participate in two trials. “One was a medication for rejection that would allow me to take one pill afterward versus 10 or 15,” she says. “The other was a clinical trial for a drug I could take during treatment that would help relieve nausea.”

The clinical trials procedures at Fred Hutchinson were well organized, Jenna recalls. “Everything they did was centralized. My responsibility was taking the pills, and they recorded everything.”

The bone marrow transplant went smoothly. Afterward, Jenna spent 40 days in a Laminar air flow room, which essentially keeps the air free of any impurities or pathogens that could lead to infection.

“When I was still in the Laminar Airflow room, I had gotten to the point that I was overwhelmed with the amount of medication I was taking,” says Jenna. “I started to skip taking the pills. The researchers came in and said ‘We can’t effectively track your response to all these drugs because you’re not taking everything we want you to take.’ They monitored me very closely.”

New challenges appeared as Jenna struggled with her body’s rejection of the bone marrow. She wound up in intensive care several times, and at one point was put into a drug-induced coma.

“I held onto the fact that I was taking that one pill versus the fact that I could have been taking many more,” says Jenna.

Gradually, Jenna’s condition improved. Seven years later, Jenna’s doctors declared her disease-free.

“The cool thing was I took that particular drug and it has a different name now, but one of my co-workers at the leukemia center was given that same drug after transplant for her disease 7 years later. They’ve made some adjustments to it, but it was really neat to see that something I had taken is still out there working, and it’s helping with rejection to bone marrow transplant.”

Now the treatments and tests are in the past. “I’m 100 % healthy. I graduated from college, met and married my

husband, and moved to San Diego.” This year, Jenna, her husband, their golden retriever and two cats celebrated her 16th anniversary of being diagnosed.

“Life is pretty darn good,” says Jenna.

Linda Morgan: Trying to Take Control of Her Parkinson’s Disease

When Linda Morgan, a 54-year-old pharmacist and mother from Asheville, NC, noticed her toe twitching, she thought it was odd but didn’t think anything serious was amiss.

“I had my feet propped up on the chair and was talking to my two sons, and saw my toe twitching. I showed it to them and said, ‘Hey, isn’t that weird?’”

That first symptom in 2004 was followed by others. “The main symptom was that my left thigh kept moving. It felt like my muscles and synapses were continually firing, which is exactly what they were doing.”

When the twitching didn’t improve after a year, Linda went to her doctor, had an MRI, and then saw a neurologist.

“He phoned me the following week and said it’s most likely I had Parkinson’s Disease. I was floored. Parkinson’s had never even been mentioned.”

Linda set out to take part in various clinical trials for Parkinson’s Disease and get whatever new treatment might be available.

In 2005, after an online search, Linda found a clinical trial at Duke University in Durham, NC, which was 3 hours away. The trial involved getting a SPECT scan, a nuclear imaging test that uses a radioactive dye and a special camera to create images. The goal of the clinical trial was to find a less expensive method (than the then-current method) for tracking certain neurotransmitters.

That trial was easy, says Linda. The researchers worked around her schedule, and she had no side effects from the dye. The next two studies Linda found were also fairly simple. One involved getting blood drawn to check genetic factors. The other study involved rasagiline (Adagio®), a drug used to treat Parkinson's Disease. Linda was in the rasagiline clinical trial for a year.

A Trial with Painful and Scary Tests

A subsequent study, however, was much more uncomfortable. It took place at the National Institutes of Health in Bethesda, MD, where Linda stayed for a week. "I got stuck pretty much everywhere they could stick you," she says. This included an IV and a lumbar puncture (spinal tap).

"That trial was real invasive. It was painful and scary," she says. "I was real glad when it was over."

Besides the pain, participating in clinical trials involved time and expense. "I had to take off from work and use my vacation time to go to the trial," says Linda. "I didn't get paid for any of the trials, although I had some travel reimbursement. The NIH paid for my flight up there and my stay in the hospital, so I got to have the 'delicious' hospital food," she laughed.

On the upside, Linda felt her tests were probably helpful, if not directly to her, then to others who had Parkinson's Disease. Additionally, she appreciated getting the results of all her scans from the NIH.

Linda's next clinical trial will involve biofeedback to lessen urinary frequency. "If it helps, then I won't have to take medicine for that."

Linda's condition has progressed since her initial diagnosis. She now has to take medication for tremors, and sometimes has trouble with speech. Still, Linda plans to keep finding trials that can potentially help her condition. She feels that the clinical trials help her psychologically.

"Taking part in the trials makes me feel like I have some control over the course of my disease," says Linda. "I don't know how realistic that is, but it makes me feel that way." ■