



## Medical Hero in the Spotlight

# Jenna Korb: Back from the Brink

Happy dreams 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 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 exam.

"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," recalls Jenna, now age 35 and the Executive Director for the [Leukemia & Lymphoma Society San Diego/Hawaii Chapter](#).

Jenna was rushed to the local hospital and soon 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. "They told me I had six months to find a match; it took me four months, which was pretty good," says Jenna.

"One of the most devastating things was losing my hair and looking so sick," recalls Jenna, "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.

"They walked in with a very thick stack of paperwork. They said, 'Here are your options, you pick one or two,'" says Jenna.

She decided to participate in two trials. "One was a medication for rejection that would allow me to take one pill after the transplant rather than 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"

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

"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 seven years later, one of my coworkers at the Leukemia center was given that same drug after her transplant. It was really neat to see that something I had taken is still out there working and helping with rejection to bone marrow transplant."

Now Jenna's 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," says Jenna. 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.



Jenna Korb

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# Can you take part in a trial while working full time?

**M**any potential volunteers worry whether becoming a clinical trial participant will interfere with their job or create problems with their boss. While clinical trials volunteers may need to do some careful planning, you don't need to be a super hero to hold a job and still volunteer.

“We want to dispel the idea that you will have to take a whole day off from work to be in a clinical trial,” says Lisa Pacitto, of [MassResearch](#). “Usually the first screening visit takes longer, because there may be a medical exam and you have to read the Informed Consent form. But in most studies, the other visits are shorter and are easier to work around your schedule.”

Often, people who work non-standard hours can talk with the trial site staff to schedule visits around their available time. “For example, shift workers can often get to their site visit before going to work, or before going home at the end of their shift,” says Karri Venn at [LMC Endocrinology Centres](#). “However, it’s a little trickier if their visit requires having fasting blood drawn, because people want to have it done early in the morning.”

If you're worried about a potential conflict between work and your trial commitments, it's wise to consider these steps:

## 1) Find out exactly what's required.

Ask how often you'll have to visit the site, how long each visit is likely to last, the schedule of visits, and how long the trial will go on.

Dr. Charles Wilcox of [Pharmacology Research Institute](#) (PRI), advises asking these questions which can give you a sense of how much time you'll spend on the trials: What is expected of me? If I arrive on time for my appointments, will I be seen within fifteen minutes or less of my scheduled appointment time? Will my calls always be answered by a “live voice” during business hours?

## 2) Be aware that many research sites try hard to accommodate volunteers.

Don't be afraid to speak up about your schedule concerns.

Patricia Larrabee of [Rochester Clinical Research](#) (RCR) says, “We do whatever we can to make visits convenient. Most patients try to come in early in the day; at lunch hour, or at the end of the day, so we are set up to see them at those times. If a trial requires fasting blood, we open up more slots early in the morning.”

Dedicated research sites also work to eliminate waiting time, which helps to keep the visit short. “Coming for a clinical trial is

different from going to your regular doctor,” says Larrabee. “We've trained our staff that nobody sits in the waiting room longer than a minute.”

Pacitto agrees that working with the volunteer helps make visits more convenient. “One gentleman who is a research subject travels a lot for work. When he starts traveling, we ask him for his travel dates. We look at his schedule and see how we can work around it so that he can get to his site visits. Also, we can start at 6:00 a.m. and get people in and out so they can get to work before it starts.”

Research sites also try to accommodate volunteers by providing extra services that can help them save time in related areas and gain other benefits.



Still, there are some jobs, such as factory workers with very limited breaks and rigid lunch schedules, that may not always lend themselves to clinical trials. Other situations may make it stressful to volunteer. “Some people's place of employment is not respectful of the fact that they need to take care of their health or wellness,” says Venn. “So they keep their disease secret from their jobs.” This may make volunteers worry about making time for their site visits.

## 3) Think honestly about your motivation.

“Maintaining your scheduled visits could seem burdensome if the trial lasts months or years,” says Wilcox. “If the trial has been going on and the subject realizes or suspects that the treatment isn't working for him, it becomes harder to stay motivated and do all the things that are required for the trial protocol.”

Motivation to improve your own condition and to assist in developing new medical treatments helps offset some of these challenges.

Since it's important to the trial that volunteers complete their scheduled visits, volunteers should weigh the challenges they face in fulfilling their trial responsibilities and discuss them with research site staff. These candid interactions will lead to the most positive—and least frustrating—situation for volunteers.

# Hockey star and family champion clinical research after losing parents

Cam Neely, a four-time all-star hockey player for the Boston Bruins from 1987 to 1996, was smashingly successful on the ice. But the talent that helped bring his teams to victory could not help save his parents from the cancer that took their lives. So Cam, his brother Scott, and sisters Shaun and Christine pulled together as a family and set out to help advance the clinical research process.

In 1997, Cam, now VP of the Boston Bruins, and his brother, Scott Neely, founded the Cam Neely Foundation for Cancer Care, part of the Tufts Medical Center in Boston. Now, all four siblings are involved in different aspects of the organization.

Scott Neely, who spoke at CISCRP's fifth annual AWARE for All - Clinical Research Education Day in Boston in October, 2009, described the events that led them to establish the Foundation.

"Our parents were diagnosed with cancer within six months of each other, and it had a devastating impact on the four kids," said Scott, who serves as Executive Director of the Foundation. Their mother, Marlene Neely, died in 1987 of colon cancer; his father, Michael Neely, died in 1993 of brain cancer.

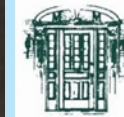
"Our experience during our parents' treatment was very difficult," says Scott. "When you walked into the hospital, you felt like you were a number. It was a cold process.

"When you enter a hospital and you have cancer, you have a whole lot of fear and different emotions," says Scott. "That was horrifying to us when trying to deal with everything. It made us realize we wanted to keep other people from having the same experience."

The Cam Neely Foundation includes the Foundation, the Neely House, and the Neely Cancer Fund. The Neely House contains eight beautiful apartments where families can stay while their loved ones receive medical care. Over 3,000 families have stayed there since it opened. The Neely Cancer Fund supports treatment

and research efforts, including the Neely Center for Clinical Cancer Research.

The Neely Center for Clinical Cancer Research focuses on experimental new treatments not yet available to the public. "Usually because of red tape, patients have to wait 6 to 12 weeks to get into a trial," says Scott. "Our mission is speeding access to new protocols." In one instance, a leukemia patient received an experimental drug in 24 hours, rather than the typical wait of 6 weeks after getting a prescription. "Trying to get the drug to the patient was a long process and at that stage, the patient often doesn't have a lot of time," says Scott. "We understand how frustrating it can be for a family when they're trying to save a life."



**THE CAM NEELY FOUNDATION FOR CANCER CARE**

*Providing comfort, support, and hope to cancer patients and their families*

Getting access to experimental new treatments without a long-wait brings hope and could be lifesaving for current and future patients, says Scott.

"Sometimes you have to be a guinea pig, but the main message is you are not only helping yourself and your condition, but helping people down the road."

Cam and Scott have become shining examples of people who want to help further clinical research in ways other than being a trial volunteer. Their example of working to raise money and awareness for research and families seeking treatment has inspired many people help further clinical research.

To find out more information on the Cam Neely Foundation please visit [www.camneelyfoundation.com](http://www.camneelyfoundation.com)

To contact The Cam Neely Foundation for Cancer Care please call 617-346-5900 or email [dlavoie@camneelyfoundation.org](mailto:dlavoie@camneelyfoundation.org).

# The Race to Test H1N1 (Swine) Flu Vaccines

Besides pumpkins and turkeys, one thing on everyone's mind this autumn is the H1N1 (swine) flu.

Pharmaceutical companies and government agencies are working feverishly to test and produce a vaccine that will protect the population. Companies have produced vaccines they believe will work, and now vaccines are going through clinical trials to test for safety; test for the best dosage, and assess whether the vaccines work as hoped.

Following is the most up-to-date information on H1N1 flu vaccine from published information at the [National Association of Allergy and Infectious Diseases \(NIAID\)](#) web site.

Some laboratory tests that help scientists learn more about the virus are done on animals. For example, tests on ferrets showed that 2009 H1N1 virus grew and spread in the respiratory tract faster than the regular seasonal flu. But clinical trials on human volunteers are at the heart of learning whether the proposed vaccines will be safe and useful. Volunteers don't need to worry about getting the flu from the vaccines: The National Institute of Allergy and Infectious Diseases states that it is not possible to become infected with 2009 H1N1 influenza virus from the vaccine.

Five drug companies are testing their own 2009 H1N1 flu vaccines in concert with the US Department of Health and Human Services. Also, the NIAID began conducting five clinical trials of two candidate H1N1 flu vaccines through its Vaccine and Treatment Evaluations Units (VTEUs). VTEU sites exist in eight locations around the country.

The NIAID trials began in July, 2009. The initial set of five trials will enroll about 3,000 people. Researchers want to learn: are the vaccines safe in healthy people of different ages; how large a dose should be given; how many doses are needed to produce an immune response; whether the H1N1 flu vaccine can be safely given along with the regular season flu vaccine, and if so, will both vaccines provide protection?

Three of the five clinical trials are enrolling healthy adults (18 to 64 years) and senior volunteers (65 years old and older). The two candidate 2009 H1N1 flu vaccines are made by Sanofi Pasteur and by CSL Limited (from Melbourne Australia).

## Clinical trials of H1N1 flu vaccine for pregnant women

Pregnant women are at a greater risk of complications from both seasonal flu and H1N1 flu virus. Since September, 2009, 6 percent of the deaths from H1N1 flu were pregnant women, according to the Centers for Disease Control and Prevention (CDC). Pregnant women who get H1N1 flu also need to be hospitalized more often than does the general public who get H1N1 flu.



Volunteer getting flu injection from doctor

Public health officials consider pregnant women as among the top priority groups to receive the 2009 H1N1 flu vaccine when it is available.

One NIAID clinical trial began enrolling pregnant women volunteers in September, 2009. The study will enroll up to 120 women ages 18 to 39 who are in their second or third trimester of pregnancy (14 to 32 weeks).

All volunteers will get two injections of the vaccine three weeks apart; half will receive 15 mg doses and the other half will receive 30 mg doses.

The clinical trial size for pregnant women is small since the amount of vaccine available is limited, and because in this case, results from a small sample of people can provide researchers with the information they need. More information is available at the [NIAID website](#).

## Clinical trial of H1N1 flu vaccine for children

Pediatric (child) trials began in August, 2009, after a panel of experts from the Safety Monitoring Committee reviewed vaccine safety data. The trials are enrolling children between ages 6 months and 17 years.

One pediatric trial will test how large a vaccine dose should be given and how many doses of vaccine are needed to produce a protective immune response. The other trial will determine whether the H1N1 flu vaccine can be safely given at the same time or after the seasonal flu vaccine is given; and if both vaccines will then produce a protective immune response. Eleven medical centers are taking part in the pediatric clinical trials.

These trials will help researchers and public policy experts select the vaccines that will be used to protect the nation. The trials illustrate the vital role and contribution of the clinical trials volunteer. More information is available at the [NIAID website](#).