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CALIFORNIA HEALTHCARE INSTITUTE

LORING LEEDS PODCAST TRANSCRIPTION

The following is a recording of Loring Leeds, a patient from City of Hope, based in Duarte, California, who was diagnosed with AIDS-related lymphoma in 1998. His long-term prognosis was bleak, but that was about to change because of a clinical trial for gene therapy that was pioneered by City of Hope researchers and physicians. He would receive a stem cell transplant designed to render bone marrow cells, HIV resistant, by using genetically modified stem cells. Loring speaks to thousands of people across the country about his life-saving experience at City of Hope. In this recording, he is addressing CHI's guests at the 2009 California Biomedical Industry Report lunch in Sacramento, January 29.

In June of 1998, I was very, very ill and after numerous tests, my doctor called me into his office and said, Loring, we finally know what's wrong with you. You have cancer, non-Hodgkin's lymphoma and you also have AIDS. I was immediately started on eight cycles of chemotherapy for the cancer and a very aggressive cocktail. But things would get worse before they would get better. I would spend the next three months in a complete delusional state. And then one day from the fourth and final stage of cancer, I began to get better. I started coming back.

After five months, I was well enough to return home to Los Angeles. My oncologist in LA wanted to be my first appointment upon my return. She was very fond of me as I was of her. She hugged me, sat me down and said, "Loring, I have good news and I have bad news. The good news is that you had a 50/50 chance of even getting into remission and you did. The bad news is that it's usually short-lived, about six months. You might want to get your affairs in order." I asked what my options were. She said, "Well, when you relapse and you will relapse, we can give you additional chemotherapy, but it may not be as effective this time around."

And then, without speaking, she wrote down a name and a phone number on a scrap of paper and handed it to me and said, "You might want to call this person." I did. And on the other end of the line was a doctor by the name of Amrita Krishnan at City of Hope. She invited me to meet with her, Drs. Rossi and Zaia. They discussed with me the possibility of a transplant for the cancer, it being the best form of treatment for someone in my position. And then it dawned on me why my oncologist hadn't suggested it. The medical community at large didn't believe people with HIV and AIDS could benefit from a transplant, much less survive one. My oncologist was, after all, a member of that community, but, as it turned out, she had done her Residency with Dr. Krishnan at City of Hope. She was aware of the work they were doing and she believed it could help me, but she was prevented from formally suggesting it.

City of Hope begged to differ with the medical community at large. They believed people with HIV and AIDS could benefit from a transplant. They believed they could survive it and they were building their case.

As if that wasn't enough, they told me about ribozine, a molecule they had designed to chop the virus in half, molecular scissors if you will, to prevent its ability to replicate. Given that a transplant was the best treatment for me, this would also be an opportune time to treat

some of my cells with this ribozine. After these cells were treated, they would be re-infused back into my body and after they reproduced, we would know if the virus was still present. In essence, we would know if my own system could genetically fight the virus. Imagine that. One own's body doing the work all by itself. No more pills. Maybe one day something as simple as getting a shot.

It was a lot to digest. Finally, I decided I would proceed with the transplant and I would participate in the research. I realized there were things in our lives of such great importance it ceases being about any one individual. This was one of those moments for me. I would proceed on all fronts.

I had my transplant on July 30, 1999 with both my own cells and my genetically modified cells and I will never forget that moment. All of the doctors and scientists and nurses and staff were in my room. Gerhard, the scientist in charge of my treated cells at Los Angeles Children's Hospital wouldn't entrust them to a courier. He personally delivered them. And they all stood at the foot of my bed and when the infusion began, there was a deafening silence and I realized that that moment was the culmination of their life's work. The years of research, the months of preparation, all for that one brief moment, that moment that was so important to them and they all wanted to be present to witness it.

Today, nine years, 184 days since my transplant, the virus continues to be consistently characterized as undetectable and there is no presence of cancer. These people are the most dedicated, the most passionate, the most compassionate people I've ever met. They are visionaries. They are the best humanity has to offer. They are the best friend our community has. They are the best friend the world community has. I truly believe our best hope for better treatments and ultimately a cure will come from the hands and the hearts and the minds of these extraordinary people. These people are changing the world. These people are making a difference. You being here tonight is making a difference.

Thank you for your generosity and interest in these efforts, efforts like the incredible work that is going on at City of Hope, the stuff science fiction is made of with one fundamental difference, it is no longer fiction. It is real. These people are real. The work they continue to do is real. I am privileged to know them. I am humbled by them, but most of all, I am grateful to them.

Thank you.

If I may, I'd like to share with you some recent findings from gene therapy research at City of Hope that began nearly a decade ago and which I have participated in as a patient at various stages of its development. I have been very fortunate over the years with opportunities to help others and contribute to the community.

On Thursday, December 11, 2008, ABC News ran a story about the first human clinical trial of a new treatment for people dealing with cancer and HIV. This unique treatment took a patient's own stem cells and engineered them with three small strands of RNA to fight HIV infection. I took part in the earlier trials that eventually lead to this ground-breaking trial. City of Hope physician, Amrita Krishnan, is noted in this story saying, "That's really what's

behind this. A way to use a patient's own stem cells to make them resistant to the virus that has already infected them."

The New Story reports, "Patients that got the cells are replicating the genetically altered HIV-resistant stem cells." With additional research and development, Dr. Krishnan is hopeful that "genetic therapy for HIV could become a reality."

Thank you.

Thank you for listening in to CHI's premiere episode of our new podcast series, Patient Perspectives. The series will examine patient experiences throughout the healthcare continuum and touch on topics ranging from access to information and care to breakthrough research improving quality of life, to solutions to the problems of rising healthcare costs and bureaucracy. Check CHI's website, www.chi.org for additional episodes.