

Case: Sandra Jensen

Born with Down syndrome and the defective heart that often goes with it, Sandra Jensen found herself sliding toward death at age 34. Her heart and lungs were giving out, and her doctor told her that to survive she would need a transplant of all three organs.

But when she applied to transplant programs, she was told in so many words that they did not perform the heart-lung operations on people with Down syndrome. As far as anyone could tell, no American patient with Down syndrome had ever undergone the procedure, which requires organs so hard to obtain that demand outruns supply by 3 to 1 and dozens of would-be recipients each year die waiting.

To Ms. Jensen, who has worked as an advocate for the rights of people with disabilities, and to a slew of supporters, this was not acceptable. They began a very public battle, gaining nationwide attention and arguing that Down syndrome, which causes mental retardation and shows up in about 1 in every 800 live births, should not be enough to automatically deprive a patient of a chance to survive.

They won. On January 23, 1996, Sandra Jensen received the requested transplant at Stanford University Medical Center, and was released on March 1. With her healthy new heart and lungs, her lips had lost their sickly blue tinge and glowed rosy pink for the first time in memory, and in that pinkness was a triumph, both personal and political.

Her case was seen by many as a test of whether hospitals could use blanket categories to deny special treatments. The hospitals argued that mental limitations of Down syndrome could affect a patient's ability to follow a complicated and demanding post-operative regime in which mistakes can mean death; and so organs in short supply would do more good if they were given to others.

"The whole time we were fighting with the medical establishment, all we were asking was that they look at Sandra as an individual," said Sandra's mother. Unlike many people with Down syndrome, Ms. Jensen had lived on her own for years and had held various part-time or volunteer jobs. Among the methods she and her supporters used was a reminder to the hospitals that under US law [the Americans with Disability Act, passed in 1993] an institution can lose all its federal funding if it is shown to have discriminated against people with disabilities.

There was no intimation in the [Stanford and San Diego] hospitals' [earlier] refusals that they did not want to give hard-to-obtain organs to a person with Down syndrome because they considered people with low intelligence inferior—though some advocates believe that sub-text was there. "We don't want to do something that doesn't have really an optimum chance of survival," said the head of the Stanford heart and lung transplant program, the surgeon who performed the operation. "There are a lot of people that are waiting, and also we're under a lot of scrutiny for the results of our program." [An institution must have a decent track-record in order to continue to be the recipient through UNOS of available organs.] *

A woman with Down syndrome whose successful fight for the right to have a heart and lung transplant brought her national attention has died, 16 months after the operation. Officials at Sutter General Hospital say 36 year old Sandra Jensen was admitted to the hospital on May 4 , 1997, and died Friday night with her family at her bedside.** The publicity the case generated prompted the California Assembly to pass a bill that prohibits doctors from discriminating against disabled people who need transplants [*although the ADA on the federal level can be argued to do that as well, making the California law unnecessary*]. The cause of death was determined to be a kind of cancer that is frequently associated with transplantation.

*--This case is abstracted from the NY Times report by Carey Goldberg, March 3, 1996.

**--This report is from US News, May 25, 1997. Both stories were located via Google.