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Larry Kramer Speaks Out Following Liver Transplant

By Jeff Getty

On Friday, December 21, 2001, after more than 12 hours of intensive surgery, 66 year-old writer and AIDS activist Larry Kramer received a liver transplant at the University of Pittsburgh Medical Center. As expected, media outlets carried the story all over the world: HIV positive people are finally beginning to receive life-saving organ transplants.



Kramer, the founder of ACT UP, was once again fighting in the trenches of AIDS activism, this time putting his life on the line. In a news story title published on December 26, the Associated Press (AP) accidentally declared Kramer dead. But Larry Kramer, and the hopes for many HIV positive individuals who are awaiting organ transplant, live on.

Kramer spoke to [HIV and Hepatitis.com](#) for his first, exclusive, post-operative interview:

"This was one tough operation - the mother of all operations!" said a recovering Kramer in his temporary Pittsburgh apartment. "You have got to want to live a lot, after the operation. For the first few days, you want to jump off the roof," he remarked about his experience in ICU recovery following the transplant.

According to Pittsburgh Medical Center spokespersons, the Kramer transplant was difficult and long, but successful nonetheless. Kramer's new liver came from a 45 year-old donor who died suddenly of a brain embolism. "You are only as old as your liver. That makes me 45!," Kramer joked. "Words cannot express the appreciation and gratitude that I feel for my donor and his family."

In a recent communication to *Survive AIDS*, a leading HIV positive organ transplant advocacy group, Kramer wrote:

"I am finally getting up to email. It has been an experience, this liver transplant.

"I want to thank you for all your quarterbacking with John Fung for me. He is a great man. He is very pleased with my progress. They took my staples out today, and also the last of my exterior draining pouches; I feel a little better each day.....

"The hardest thing is eating enough and drinking enough. He said my old liver was really disgusting, and it didn't have much time left. The [adefovir](#) [an experimental anti-hepatitis B drug] obviously bought me the extra time I needed to find and get listed for a liver. If it hadn't been for the adefovir I guess I would be dead.....

"John got me a great liver with no viral complications. I'm lucky. All the pills are tolerated well, except for I guess the Viracept [an HIV protease inhibitor], which gives me a lot of diarrhea. I am working hard to get back into shape.....

"I am very touched by all the outpourings of care and concern and love. I have to get better! Thank you again. This operation has got to be viable for us. Whether everyone can get through those first couple

of days is another question."

Kramer will be staying in Pittsburgh for the next few months so that he can be close to the medical center and near the medical experts who may need to adjust drug dosing or intervene in emergency situations.

Kramer is by no means out of the woods, according to his caregiver Rodger McFarland. "Larry has a team of doctors, experts and close friends like myself and David, watching over him at all times." said McFarland.

McFarland stressed over and over that the most important part of the successful transplant was not the operation, but the recovery. "He had a team of professionals dogging him 12 hours a day, he worked his ass off and was a good soldier" remarked McFarland.

According to a past interview with Pittsburgh surgeon Dr. John Fung,

who performed Kramer's transplant, *20% percent of all regular liver transplant patients do not survive.*

In HIV patients the survival rate is lower still. Depending upon which data one reviews, survival rates since 1997 have been around 60 or 70 percent. In 1990, survival rates were very low. Few people lived more than a year or two.

With each successive transplant, doctors, patients and advocates are learning more and more about what it takes to ensure HIV positive patient survival following complex organ transplantation. As new problems are encountered and overcome, the pooled body of knowledge increases, thereby increasing survival rates for future patients.

Kramer is a good example of this important learning curve. At 66, with a detectable [HIV] viral load, a rapidly failing liver, catabolic wasting, ascites (fluid retention in the abdominal region) and serious blood supply problems, Kramer's transplant posed some of the toughest challenges yet for the liver transplant medical team. Kramer feels lucky to be alive.

And the lessons for the HIV community are important as well. Patients and their advocates learn, often the hard way, that organ transplantation is one of the most arduous and difficult projects one could ever tackle. The road to transplant has many pitfalls. Many patients never live to see an operation.

"People have no idea how much work you have to do," said Kramer. He had shopped around at various hospitals that perform liver transplants. One hospital, Mt Sinai in New York City, considered Kramer for transplant, but it was rumored that they withdrew all offers when they discovered he had a complicated blood supply problem in the artery leading to his then-failing liver.

"I had to spend two months just trying to qualify for emergency consideration at Mt. Sinai," he mentioned. Kramer wasn't convinced that he was excluded because of blood supply problems. "These surgeons would not operate unless I got my blood to be undetectable [for HIV]," he said.

In a previous interview Kramer also remarked that he did not feel welcomed or wanted at Mt Sinai. Other issues such as homophobia, AIDS-phobia and ethical concerns about "wasting good organs on HIV positive patients," or the fear that donors might stop giving organs if they find out PWAs are receiving them, have all influenced and slowed HIV positive transplant progress.

In a recent *New York Times* interview, Dr. Fung stated that homophobia has been one of the problems in moving HIV positive organ transplants forward. Such homophobia is veiled, and never openly admitted.

Often it is hidden in the policy decisions that have designed the screening process. Survive AIDS has interviewed numerous patients who were turned away by transplant "gate-keepers" because they did not meet rigid candidacy profiles, lacking such things as good family support systems.

As Kramer learned well, good family support is absolutely essential for patient recovery and survival, but large institutions are slow and reluctant to recognize gay friends and supporters as family.

Other factors regarding gay men's life styles can also serve to disqualify them from organ transplant. For example, honest answers to questions such as "Do you drink or take drugs?" can lead to immediate disqualification if the answer becomes "Oh, once in a while." Many institutions simply deny access to HIV positive patients outright, even though UNOS rules, Medicare and many private health insurance companies do not.

Still, Kramer is quite happy to be alive and to have survived the ordeal. "I am happy now, I want to write my book. I actually like it here in Pittsburgh. Do you know of any good restaurants here?, he quipped.

Following the transplant Kramer received cards and email from all over the country. "I never felt so much love," he said. After further recovery Kramer says he plans to get more involved in transplant activism. "We need to get the laws changed so that all who can, must donate organs," he said.

Indeed, other activists are looking into legislation that will allow a dying donor's previous donation wish to supercede that of immediate family member's powers of attorney. Indicating that one wants to donate one's organs on a driver's license does not guarantee such an event will take place. Often family members will legally and ultimately, decide whether or not organs will be gifted. Grieving and shocked family members are all-too-often reluctant to allow organ removal - even when the donor has indicated his/her wishes to do so on a driver's license.

According to UNOS, of the nearly 5,000 liver transplants performed in the U.S in the year 2000, only 11 went to HIV positive patients. At the same time it can be assumed that many useful organs were refused because they were considered high-risk, coming from gay men. Organ donor guidelines mimic blood donation rules; gay men are usually not included.

As for other HIV positive organs being recycled and gifted to other HIV positive patients, the medical community will not even consider it. While claiming that such organs are unviable, and infected with possibly drug-resistant HIV strains, according to inside sources, the main concern why these organs go unused is never mentioned: surgeons do not care to operate on patients with detectable HIV in their bloodstreams, which put them [the surgeons] at some risk for acquiring HIV themselves. When Kramer was asked how he felt about Dr Fung's personal risk in performing his transplant, he remarked, "He (Fung) didn't seem to care. Although you should have seen the spacesuit he was wearing!"

Of more than 100 centers performing organ transplants in the US, only two or three actively operate on HIV positive patients. Though a protocol has long been in the works to study such transplants at 17 sites nationally, it is not yet and may never be NIH-funded.

Only through changing consciousness and perhaps as the result of high-profile transplants like Kramer's, will private insurance and reluctant hospitals allow access to HIV positive individuals. Such political understanding may well be the reason why Pittsburgh, a leader in progressive transplant thought, went ahead with Kramer.

In the long-standing debate over whether or not to transplant "unworthy" members of society, Dr John Fung and his colleagues have long repeatedly that transplants be available to all who need them, regardless of who they are or what they might have done. And this includes HIV positive gay men and even prisoners on death row.

Jeff Getty jeffgetty@earthlink.net

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