Liver Lovers

When your liver goes South, an organ transplant may be your final destination. Mark de Solla Price takes us along on his partner Vinny's journey to get one.

February 1, 2001 By Mark de Solla Price

November 13, 2000
Today my husband, Vinny Allegrini, and I are in a strange no-man's land, camped on the 14th floor of a bland office building on Mount Sinai Hospital's sprawling 10-block campus between Harlem and the monied enclave of New York City's Upper East Side. We're here for the second of three full days at Mount Sinai's Recanati/Miller Transplantation Institute.

This is the nation's third-largest liver transplant center, where more than 175 transplants have been performed in the past year. More important for us, it is one of the few hospitals in the world that will consider someone who is HIV positive as an organ transplant candidate. Of 120 transplant centers in the U.S., only the University of California at San Francisco, the University of Pittsburgh Medical Center and Mount Sinai have ever done organ transplants for HIVers, although hopefully a dozen other centers may perform them soon.

Vinny and I landed here because after more than a decade of chronic hepatitis B coupled with the toxic effects of HIV drugs, Vinny's liver is failing. We don't know how much longer he has with all the stopgap measures we've been taking, but we do know that the only treatment option for end-stage liver disease is a transplant. Once we accepted that last summer -- which wasn't easy -- we began to do whatever it takes to make one possible.

I've had HIV for 20 years, and Vinny has been living with both HIV and hep B for 12. In the eight years we've been together, we've become quite a health-care duo, each the other's caregiver. Our doctors joke that we double-team them: Regardless of who has the appointment, we both show up. When our insurance company, Physicians Health Services (PHS), stopped covering office visits for our testosterone injections, Vinny and I learned how to give each other the intramuscular shot with those intimidating two-inch needles. We've figured out together how to do research and work the benefits system. But even with all these skills, the journey toward a transplant is sure to be long and difficult, with no certain success.

Transplants are insanely expensive, even compared with the enormous expense of HIV care: Kidney transplants can cost up to $250,000; liver transplants, up to $1 million. Post-transplant meds can cost $20,000 a year for life.

Beyond the dollars involved, donated organs are incredibly scarce and the waiting list grows steadily. In 1999, 4,698 liver and 12,483 kidney transplants were performed, while more than 4,500 people died waiting for an organ to become available.

Because of the huge expense and the scarcity of organs, the evaluation process is extremely complicated. The goals are to prioritize those most in need and to reject those unlikely to recover from surgery. In the past few days at Mount Sinai, we’ve undergone a mind-numbing array of tests, interviews and exams. By the end of the process, Vinny will have completed a medical assessment by the liver transplant team (four doctors and 13 vials of blood!), two cardiology tests, a chest X-ray, TB screening, abdominal CT scan and ultrasound, evaluation of his HIV and hep B infections, a dental exam and sessions with a psychiatrist and a social worker.

A few years ago, simply having HIV was enough to knock you off the list. Perhaps biased by AIDS ignorance, experts feared both that the strong meds used to prevent organ rejection would destroy PWAs’ already-suppressed immune systems and that HIVers wouldn’t live the five-plus years postsurgery to justify the use of donated organs. But due to the advent of HAART, along with activist pressure from Jeff Getty of Survive AIDS (formerly ACT UP/Golden Gate) and others, liver and kidney transplants have become available to a very few HIVers over the past two years.

“Historically, HIV precluded any possibility of liver transplants,” says Sam Sigal, MD, the attending transplant hepatologist at Mount Sinai. “The combination of HIV and immune suppression would have been devastating. However, with new, effective HIV treatments, the issue has been reconsidered. Now transplants are being performed in selective cases.” So far, just 13 HIVers have received a liver, and five a kidney. All but two are still living. And it looks like serious infections in positive transplant recipients are no more frequent than in others. In December 1998, Alan Hext, of Palm Springs, became the first HIVer to receive a liver transplant; though he was hospitalized once for an oral infection (probably related to the immune-suppressive antirejection drugs), overall, he’s quite healthy, with high CD4s, an undetectable viral load, a thriving liver -- and a new baby son.

This anecdotal data is encouraging, but Vinny and I know we’re in fairly uncharted territory. The other day, Vinny told me, “It’s scary to hear that only one operation like mine has ever been performed at Mount Sinai, and that our insurer has never approved coverage for an organ transplant for someone with HIV. But being told that your liver is beginning to fail puts a lot of things in perspective.” We just keep crossing one bridge at a time.

June 16, 1999
Today is the anniversary of the day Vinny and I first met as “prayer partners” at an HIV workshop led by spiritual guru Marianne Williamson. Though we both believed then that we were beyond romance, a life-challenging condition can make events progress at warp-speed. I was living in New York City working on a book, and Vinny was cutting hair in West Hartford, Connecticut, but that summer we began to live together. We’d alternate between staying with Vinny’s ex-lover, Gregory Dean, in West Hartford, and my ex in New York City. Our exes form a kind of family for us; Gregory, in particular, would soon become essential to Vinny’s future.

In recent weeks, Vinny has developed anemia and a mysterious, intense pain in his GI tract. So instead of celebrating our six years together, we headed off to our GI and liver specialist, George Haroutiounian, MD. There, Vinny had to undergo an endoscopy, in which they shove an 18-inch robot arm down your throat, while I got to watch live on a video monitor. I knew Vinny's throat was supposed to look pink and smooth, but instead I saw swollen, lumpy veins. Vinny had internal bleeding from leaking varicose veins in his esophagus.

It turns out that Vinny's chronic hepatitis B, along with the antiretrovirals he's been on since 1995, has caused cirrhosis of the liver. Because the liver filters impurities from the blood, when scar tissue (cirrhosis) clogs the liver, pressure can build up in the plumbing between the heart and liver, causing the veins to balloon and leak. Difficult to diagnose and treat in time, this internal bleeding is often fatal, so it's critical to watch for. It's also pretty common: Many HIVers are coinfected with hepatitis, and each year about 10 percent of people with hep B and 85 percent of those with hep C end up with chronic hepatitis -- the leading reason for liver failure in the U.S.

For the next year, Vinny will follow a very aggressive treatment, entering the hospital on a monthly basis for endoscopic surgeries to "band," or cauterize, the leaks. These procedures are extremely painful because when you have liver damage, only tiny amounts of anesthesia can be used. Luckily, our surgeon, Leslie Seecoomar, MD, is, in Vinny's words, "truly gorgeous -- though hetero -- a Ken doll with blue-black hair." This helps Vinny distract himself during the surgery. One doc told us that Vinny holds the Roosevelt-St. Luke's Hospital record for the most successful endoscopic surgeries.

January 12, 2000
Vinny had just left on Amtrak to visit his family in Hartford and I was about to head out the door to the gym when I got a call from our regular HIV doc, Howard Grossman, MD, with the results of Vinny's latest blood tests. His hematocrit (the percentage of blood made up of actual blood cells) was dangerously low. A normal reading is 40 to 50 percent; Vinny's was under 20. Apparently he'd had another serious bout of internal bleeding.

It seemed to take forever for Vinny to arrive in Hartford and call in. I told him to get on the next train back. While I was waiting at the station, Haroutiounian's office paged me: "Don't come to the office. Go straight to the emergency ward for a transfusion."

Vinny tends to have a great attitude, and I'm the sort who stays calm in an emergency, but the next 24 hours were tough for both of us. This was the height of the flu season, and the hospital was packed, complete with TV crews covering the pandemonium. Luckily the transfusion stabilized Vinny, who was once again endoscopically patched up. By the time we got home, we'd both been up for 48 hours. We collapsed on the bed and didn't leave the house for two days.

May 31, 2000
Life barely seems to get back to normal anymore. While we were in Copenhagen to celebrate my 40th birthday, Vinny had yet another bout of internal bleeding. We rushed back to New York to find that his condition had so deteriorated -- Seecoomar said his throat looked as if no repairs had been

done at all! -- that drastic action was required. Vinny got a TIPS (transjugular intrahepatic portosystemic shunt) installed in a three-hour, high-tech procedure -- a catheter was inserted through his neck and the shunt implanted by remote control. The shunt will serve as a partial liver bypass to relieve the pressure. Vinny's internal pressure number went from 15 (dangerously high) to 6 (the low end of normal) after the surgery, which greatly reduces the likelihood of more internal bleeding, at least for now.

As with most HIV remedies, the downside soon emerged: With all that blood bypassing liver filtration, so many toxins built up that Vinny developed "portal-systemic encephalopathy," a condition that causes extreme fatigue, mental confusion and motor skill problems. The classic test is to ask the patient to put his or her arms out, palms forward, like a traffic cop signaling to stop. People with encephalopathy will involuntarily flap their hands, which, scarily, is exactly what Vinny did. It was as if he had instant Alzheimer's. Although serious, the condition is generally reversible with drugs. In Vinny's case, we used lactulose (Kristalose) and neomycin, and once again he rebounded.

August 21, 2000

Today, as we headed for our monthly checkup with Grossman, we were feeling pretty happy about Vinny's condition. He's had to rest a lot, because the liver damage taxes his system, but on good days he works to build his stamina with moderate exercise. We had the sense that his health could remain stable for quite some time. Unfortunately, Grossman didn't share this view. Although Vinny could be stable for a few years, Grossman said, his condition also might destabilize quickly to the point where his only option would be a transplant. Grossman strongly suggested that we waste no time beginning that lengthy process. If we waited until Vinny was desperate for a transplant, it might be too late to get one.

Both Vinny and I left feeling shaken up. But within days, we set up our first meeting with Sigal, the transplant expert at Mount Sinai. The current guidelines, he told us, limit access to those who have never had an opportunistic infection or a CD4 count below 200, have zero viral load for both HIV and hepatitis, and are otherwise healthy. Technically, Vinny doesn't qualify, but his PCP and low CD4s happened years ago, prior to his taking HAART, so we're hopeful that he's close enough for the folks at Mount Sinai. Once Vinny's intensive evaluation is complete, the Recipient Review Committee will make a final decision.

August 24, 2000

This process has been Kafkaesque. Before you even start the headache of an evaluation, you must be preapproved by your insurer. Our HMO-style PHS naturally wanted this costly process taken care of "in the network" of contracted facilities. However, none of the three hospitals that do transplants for HIVers are in the PHS network. So Mount Sinai refused Vinny's insurance and referred him to New York University Hospital; NYU, which doesn't do transplants on HIVers, sent us back to Mount Sinai, which sent us back to NYU. This Catch-22 would have been funny if Vinny's life weren't hanging in the balance, but we were freaked.

Finally, today, a PHS supervisor was able to break this infinite loop and authorize us "out of network," at least for the evaluation. In fact, PHS is now covering the evaluation stage for several HIVers, but since no one has yet progressed to surgery, the jury is still out on whether PHS will cover the transplant itself. And our epic insurance battle is hardly unusual for people with HIV who need a transplant.

The next obstacle was a legal one: Vinny's HIV meds cause extreme nausea and vomiting. But because all of the approved antinausea meds are metabolized in the liver, if Vinny were to take them, he'd end up in the hospital with encephalopathy again. One of Vinny's regular doctors suggested that he try medical marijuana, which Vinny used with great success. However, Mount Sinai classifies use of medical marijuana as "illegal drug use" -- if Vinny continued to use it, he'd be rejected as an "active drug addict." So a few months ago Vinny stopped using marijuana and signed a contract allowing random drug testing.

Now he has to get used to constant nausea and throwing up onto the curb as we walk along the street. This isn't exactly fun, but we had no choice. This isn't a rule we've been able to bend -- yet.

September 1, 2000

If Vinny is accepted into the transplant program, he'll be added to the UNOS (United Network for Organ Sharing) list -- a centralized database to match up the scarce organs with those in need. Matches are based on medical urgency, time spent on the list, compatibility of donor organ (for livers, it's blood type and size; for kidneys, tissue type matters, too), and location. Potential recipients move up the list over time and as their condition worsens. That's when the final Catch-22 kicks in: It's common for people to wait years before they make it to the top of the list -- so by the time they get to undergo this major operation they're usually critically ill. Not ideal.

Here's the silver lining: We recently found out that once Vinny is accepted into the program, he may have a better option: a "living donor" transplant. In this procedure, first performed in 1989, a healthy person donates about 60 percent of his or her liver, which, unbelievably, fully regenerates in both the donor and recipient in six to eight weeks. (A kidney donor gives up one kidney, and survives fine with the other.) The quality of an organ from a living person is generally better than one from a cadaver: It can be carefully prescreened and then transplanted quickly, rather than spending a day or two on ice in transit. But this procedure is technically far more difficult than transplanting a whole liver because the blood vessels and bile ducts have to be carefully divided between the donor and the recipient.

Nearly a third of all kidneys transplanted come from living donors, but fewer than 1 percent of livers do. The first such operation in New York state was performed only two years ago. The procedure's been done just once at Mount Sinai on an HIVer (according to the senior clinical coordinator there, that person is still doing well after a year). The biggest advantage of a living donor is that we won't have to wait for the transplant until Vinny gets critically ill. Of course, we need to find a donor with the same blood type as Vinny, the same physical size, in great health and -- this rules me out -- HIV and hepatitis negative. So far no living donor at Mount Sinai has had a serious complication, but as with any major surgery, there is some risk.

Something incredible happened this evening when Vinny was driving to a restaurant with Gregory, his ex. Suddenly, Gregory, who has the same blood type as Vinny, turned to him and asked if he might be able to donate part of his liver. Vinny says that he was completely speechless for a long moment, and then they both broke down crying, hugging and crying. When Vinny called me with the news just now, I started crying, too. “Vinny’s been my best friend for more than 17 years, even though we went our separate ways romantically,” Gregory would later tell me. “He’s pretty remarkable, and it’s been rough to see all that he’s had to go through medically. He’s my true family -- when I heard that I might be able to qualify as a donor I just knew I wanted to do it.” Vinny and I are blown away by Gregory’s act of love -- and extremely grateful.

Once Vinny is approved as a transplant recipient (think positive!), Gregory will face his own array of testing to determine whether he’s in fact a suitable donor -- a process that may take several months. “If everything works out,” Gregory will point out, “we’ll all be living together for a while as Vinny and I recuperate from successful surgery.” It’ll be just like the old days, when we all shared Gregory’s apartment in Connecticut.

October 3, 2000
For now, we’re focused on getting Vinny “on the list.” Our attitude is to make a liver transplant viable but put off needing one for as long as possible, with steps like his shunt, the endoscopic surgeries and therapies for liver disease symptoms -- the topic of today’s visit with Haroutiounian.

While many people in the early stages of hepatitis find that treatments with interferon fend off liver damage, Haroutiounian said that Vinny’s cirrhosis had progressed too far for the drug to be of use. Instead he put Vinny on the hep B drug Epivir HBV, a.k.a. 3TC -- the same drug used to fight HIV but in a much lower, 100 milligram per day dose. (Note: HIVers who have never taken 3TC may want to take a pass, because the low dose may promote drug resistance.) On this med, Vinny has consistently tested negative for HBV DNA -- a viral load measure for hepatitis.

We’ve also been swamped with helpful suggestions for liver-supportive foods and herbs; several experts recommended nutrients that raise liver levels of glutathione (N-acetyl cystine, vitamins C and E, alpha-lipoic acid and glutamine) as well as the antioxidants silymarin (milk thistle extract) and coenzyme Q-10. Some liver experts recommend avoiding animal protein (with its high ammonia content) to reduce encephalopathy, but with Vinny’s wasting and nausea, he wasn’t able to tolerate this diet. So far the only thing that’s clearly helped Vinny’s liver labs is the milk thistle, at 400 mg per day. When he takes it, his liver scores improve; when he stops, they get worse. Hardly a clinical study, but good enough for us.

Just like living with HIV, liver disease is a game of playing for time. “We’ll just play the cards as they are dealt and keep moving forward,” Vinny says. “There is a remarkable amount of power in just doing it and letting the details take care of themselves.”

December 1, 2000
Vinny and I spent the evening at an AIDS benefit at Carnegie Hall, and tonight we’re full of hope. This is the strange, wonderful future we’re visualizing for Vinny: six to eight hours of transplant

surgery, followed by two to three weeks in the hospital and a footlong scar above his belly-button; and then a barrage of drugs to prevent infection and organ rejection. After recovery, doctors say Vinny's low stamina should abate; three to twelve months after surgery, he should be able to work again and lead an active life.

In the earliest days of organ transplants, rejection was sometimes fatal, but with improved antirejection drugs -- cyclosporine (Neoral), tacrolimus (Prograf), prednisone and azathioprine (Imuran) -- this has become extremely rare. Today the big dangers are hepatitis recurrence and complications brought on by the immune-suppressive antirejection meds themselves, especially bone and cardiovascular disease and opportunistic infections -- a special concern for HIVers. Common infection-fighters include Bactrim to prevent PCP, acyclovir to prevent viral infections, clotrimazole (Mycelex) to prevent oral thrush, and nystatin, an antifungal, to prevent vaginal infection. Doctors also recommend aspirin to decrease blood clots in the new arteries and veins. (A warning: Laurie Carlson, UCSF's transplant study coordinator, informed me that many transplant meds interact with HIV meds and affect absorption of both classes of drugs, so dosing must be regulated very carefully. In fact, Dr. John Fung, Chief of Transplant Surgery at the University of Pittsburgh, attributes one of their two HIV positive liver transplantee deaths to the lack of knowledge about the interactions between these drugs by the patient's own non-transplant doctors.)

We might expect Vinny to have at least one episode of organ rejection in the first three months; this requires hospitalization but is usually treatable. Since Vinny has hep B, he'll also have to get lifelong monthly infusions of hep B immune globulin (HBIg) to reduce the likelihood of hepatitis recurrence.

Kidney and liver transplants are enormously expensive and complex procedures. But they have a good track record (they've been performed since 1954 and 1967, respectively) and survival rates are high: about 80 percent for liver recipients and 95 percent for kidney recipients. Some live up to 30 years after surgery. While it's too early to predict long-term success rates for people with HIV, our message to those with serious liver or kidney disease is: It is possible. As for us, we hope to lead a long and happy post-transplant life together.

December 8, 2000

Just as this article is going to press, we get a call from Sigal at Mount Sinai with some disturbing news: Vinny's latest liver CT scan shows two small tumors. Given that Vinny has cirrhosis and hep B, there's no question that these are liver cancer. Such small tumors are common in people with extensive liver damage, and tend to be well behaved, but Vinny will have to repeat the CT scan every two months to monitor the situation. If the tumors start to grow, he may have to begin anticancer treatment on top of everything else; more than ever, a transplant is our only hope. Optimists as always, Vinny and I are focusing on the positive: These tumors are a UNOS "listing criteria," so they may greatly expedite Vinny's acceptance into the transplant program.

A Liver Runs Through It

Gregory Dean on three-way love, gay friendships and the gift of life.

I'm orIginally from South Carolina, and ever since I came North, Vinny's been the mainstay in my life. We met back in July 1983, and were partners for six years; by now he's seen me through four relationships. Vinny always makes sure I have a place to go for the holidays. He looks out for me. Whenever I have problems, and no one else in the world to talk to, he's there. Once, when I was on the verge of a breakup, my partner punched me in the face. The first thing I did was call Vinny, crying hysterically. And he knew what to do; he even called the cops and made them come to the house.

When I heard that a living liver donor was a possibility, I immediately thought, "I can't imagine this world without Vinny." I didn't talk to anyone else, because they'd all say, "No, don't do that." Making the offer just felt natural.

I'm not afraid of what's ahead. I've always been fairly healthy, and from what I've read, your liver regenerates itself. A couple of friends think my decision is absolutely wonderful, but one thinks I'm crazy, that it's too risky. Am I going to tell my family? No. They have a tendency to freak out.

I believe that we're all part of a universal community. You know that thing about karma, how what goes around comes around? You help someone today, someone else may help you tomorrow. I've seen too many people go in ugly ways -- including a boyfriend who died of AIDS in 1994, who went down very, very quickly -- and it just isn't fair. It could be any of us. I hope, after all the tests, it works out for me to do this. Because Vinny is an amazing person.

Resources

To Give
If more people signed up to be organ donors, livers and kidneys wouldn't be so scarce. For HIV and hepatitis neggies, here's how to do the right thing:

Call the Coalition on Donation/Share Your Life Campaign
at 800.355.SHARE to get info and your donor card, or check out www.shareyourlife.org.

To Receive
If you or someone you love is coping with organ damage and may need a transplant in the future, start planning now:

United Network for Organ Sharing
the definitive resource on transplants, at www.unos.org or 888.TXINFO1

American Liver Foundation
for info on liver disease, at www.liverfoundation.org or 800.GOLIVER

National Kidney Foundation

for info on kidney disease, at www.kidney.org or 800.622. 9010

HIVandHepatitis.com
an info-packed site all about HIV and hepatitis co-infection, at www.hivandhepatitis.com

Survive AIDS
a San Francisco-based activist group that has taken the lead on advocating for transplants for HIVers, at 415.252.9200 or www.surviveaids.org

Centers that perform HIVer organ transplants:
University of California at San Francisco (UCSF) at 415.502. 8322 or www.ucsf.edu; University of Pittsburgh at 412. 648.3200 or www.sti.upmc.edu; Mount Sinai Medical Center at 212.241.8035 or www.mountsinai.org

To share
For personal updates from me and Vinny Allegrini on our saga, visit our website: MarkandVinny.com