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Surprise for Organ Donors: Unexpected Medical Bills

By Mary Ann Roser

A year ago, Philip Knisely looked across the room at a co-worker and was moved to tears. The man's pallid skin and labored movements were the picture of someone dying. Knisely knew he had it within him to save the man's life.

Knisely offered José Luis Vara Jr., a father of three, his kidney. He didn't know Vara well, but "I wanted to help a family," said Knisely, who lost his father to Parkinson's disease in 2005. Within six weeks, on Dec. 30, 2008, surgeons at St. David's North Austin Medical Center removed Knisely's left kidney and put it in Vara, who had been on dialysis for 3½ years because of polycystic kidney disease — the same ailment that had killed Vara's father.

The hospital assured both men the surgeries and any donor-related complications Knisely might face would be billed to Vara's insurance, as federal law prescribes. But that is not the way it worked out.

Knisely, a 53-year-old tax analyst for the state comptroller's office, has received numerous notices that his insurance company was billed thousands of dollars by the hospital, doctors and other medical providers for treatment of post-surgery complications such as pancreatitis, an inflammation of the pancreas. Knisely said he also has been billed directly several times and has been contacted by a collection agency because he wouldn't pay.

"I've been appalled about how this has been handled," he said.

Donors getting billed for transplant-related care has been a national problem for years, said Donna Luebke, a nurse practitioner in cardiology at MetroHealth Medical Center in Cleveland. She donated a kidney to her sister in 1994 and has become an advocate for living donors nationwide.

"Right now it is the issue for living donors in this country," Luebke said. "I know of donors who have paid thousands of dollars out of pocket for complications."

There is no data on how often that occurs, but most physicians and others in the transplant community say they hear the complaint from donors. Last year, 16,520 kidney transplants were performed in the United States, including 36 percent involving living donors.

Since 1972, Medicare has covered the cost of kidney dialysis and transplants for people with end stage kidney disease. That law includes covering the cost of the transplant and related complications for kidney donors. For the recipients, Medicare requires that the bills first go to their private insurance — if they have it — before Medicare.

But kidney donors and their advocates say donors still get improperly billed.

"Each state dictates its insurance laws, and it becomes very, very complicated," Luebke said.

Kimberly Tracy, a 51-year-old dialysis nurse who lives in Dayton, Ohio, donated a kidney to her nephew in 2001 and said she had to provide her insurance information to the hospital to get pain medication from the surgery.

"It was either that, or I was going to have to suck it up and go home without any," she said. She ended up using her own insurance to pay for the medicine and other transplant-related bills, including a later surgery, she said.

Tracy started a Web site, the Living Organ Donor Advocate Program, to educate and provide support to living organ donors. She advises donors to get a written explanation from the hospital about how costs will be covered. Tracy said she met with congressional staffers in 2002 to discuss issues living donors face such as being billed improperly. "We have made senators and congressmen aware that CMS (the Centers for Medicare and Medicaid Services) is not adhering to the law, yet they allow this to go on," she said.

A Medicare spokeswoman said she was unfamiliar with Tracy's allegations.

"We cannot respond to general allegations of non-compliance or non-enforcement of our policies," Medicare spokeswoman Ellen Griffith wrote in an e-mail.

North Austin Medical Center officials said they are working hard to fix what they say are bills inadvertently sent to Knisely, and they say they took steps last month to prevent donors from being billed in the future. They issued identification cards donors can use at the hospital for a year, regardless of the reason, so their private insurance isn't billed by mistake, said James Pittman, the hospital's transplant program director.

"We're going to do everything possible to make sure he's not out a dime," said Cindy Sexton, the hospital's chief financial officer.

Pittman said other donors have been billed on occasion, but the hospital has been able to correct errors quickly when patients bring in their bills.

Issues for donors

Living donors face other problems, too, Luebke said. Some develop chronic health problems after surgery and lose their health insurance or can't get coverage because some insurers say they now have a pre-existing medical condition.

Knisely said the hospital did not tell him that if ever he loses his insurance with the state comptroller's office where he and Vara, 52, work, some insurers might consider a single kidney to be a pre-existing condition and a possible reason to deny future coverage. Pittman said the hospital provides that information orally.

Laura Odom, a 52-year-old mother of five in Wheaton, Ill., said after she donated part of her liver in 2002 to her sister-in-law, who had liver disease, she was billed incorrectly for the transplant and for treatment for later complications. She said it took about six months to straighten out the billing, but she's had ongoing health problems since the transplant, including chronic pain and a grapefruit-sized hernia in her diaphragm that led to serious intestinal problems.

She can no longer get private insurance because she is considered to have a pre-existing medical condition, she said. She is on Medicaid now.

Everything was done so hurriedly to save her sister-in-law, she said, that she didn't know that in the process of donating part of her liver doctors also would have to remove her gallbladder. That has contributed to her digestive problems, Odom said.

"In retrospect, I would have done things differently. I would have had a notebook and gotten things in writing," Odom said. "I have a recipient who has her life back, and now I'm sicker than she is."

Kidney donation is generally considered safe, according to research published earlier this year in the *New England Journal of Medicine* on nearly 3,700 donors going back more than 40 years. The study, touted as the largest and longest on long-term outcomes of living kidney donors, said donating a kidney doesn't appear to have any long-term health consequences for the donor.

It found that most donors lived a normal life span and were as healthy as the general population. Donation didn't raise the risk of having kidney failure later, and donors generally had an excellent quality of life, the study said.

Problems with billing

Knisely has had three medical complications from his transplant, and he and the hospital trace his billing problems to the first one. He went to the North Austin Medical Center's emergency room with gastrointestinal symptoms on Jan. 9, six days after he was discharged following the donor surgery. Knisely was diagnosed with viral gastritis, and the hospital billed his state-provided health insurance because the problem was not considered to be transplant-related, Pittman said. When Knisely was discharged on Jan. 12, doctors changed his diagnosis to pancreatitis, which was determined to be a donor-related surgery complication, Pittman said.

By then, Knisely's insurance had been billed \$18,831 in hospital charges alone. Knisely took the statement to the hospital after it arrived in March, and Pittman said he notified the billing department that the charges should go to Vara's insurance instead. Pittman said Knisely's insurance plan was paid back Oct. 9 — seven months after the bill arrived and one day after hospital executives met with a Statesman reporter to discuss Knisely's case.

Knisely said he also received separate bills from the doctors who treated him.

Pittman said Knisely hasn't cooperated when the hospital asked him to bring in every bill he's received. He added that doctors aren't employed by the hospital, and "we sent formal documents to the offices of physicians that explained how and who to bill" dating back to December. Pittman said he didn't know why it took so long for the hospital to pay back the state health plan, which also was billed for care related to the other two complications.

North Austin Medical Center has done 397 kidney transplants since 1996, Pittman said. Of the living donors who had surgery last year, Knisely was the only one who had complications that required hospitalization, Pittman said.

"The bottom line is that we are so thankful to Philip for being a living donor, saving the life of his colleague," he wrote in an e-mail. "We are very sorry about the confusion in billing that stemmed from the hospital admission in January when his diagnosis was changed and we want to help him work through those bills so that he will not owe any money. As soon as he brings those bills in to us, we are confident that we can do this."

Knisely said he would be willing to give the hospital the few bills he has not provided if hospital officials would explain to him and Vara how their billings were handled from the beginning.

Luebke and other advocates say that as Congress debates health care reform, it should require Medicare to see that donors are covered, as the 1972 law says, regardless of conflicting policies in states. They favor proposals by congressional Democrats that forbid insurers from discriminating against donors for having "pre-existing conditions." And some

advocates also favor a registry of living donors so it is easier to track them, including any future medical problems.

"This is the time to incorporate new thoughts and take care of living donors for the consequences of their donation," said Dr. Connie Davis, a professor of medicine at the University of Washington and vice chairwoman of the living donor committee for the United Network for Organ Sharing, the national organization that matches and distributes organs.

In Texas, the health plan for state workers insures 528,000 state employees, higher education workers, retirees and dependents — nearly 90 percent are enrolled in the Blue Cross/Blue Shield HealthSelect plan, including Knisely and Vara. But until last year, the state health plan did not cover organ donors' transplant-related costs — despite a federal law that says donors shouldn't pay for those costs.

Under the old policy, organ recipients were required to pay the donor's costs out of pocket, and in some cases the donor's insurance may have been billed for some transplant costs, said Mary Jane Wardlow, a spokeswoman for the Employees Retirement System of Texas, which administers benefits for current and former state employees and their families.

The state changed the rules last year in response to questions by HealthSelect members, Wardlow said. The new policy says that if the donor and recipient are both covered under the HealthSelect plan, the bills are paid "under their own names/policies." Wardlow said the intent was to cover donors' costs, but she acknowledged the wording is confusing and "the state is in the process of clarifying that (to mean) donors are not responsible for these costs."

Knisely said his questions about the state policy prompted the clarification; Wardlow said she could not comment on specific cases.

Knisely says that despite the billing problems and three hospitalizations for complications, he does not regret helping Vara. "This was a tremendous experience to help someone as kind as this person," he said.

Vara, who is healthy now, said he feels terrible about the trouble Knisely has experienced.

"It shouldn't happen to him," he said. "Everything he has done was so good."