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U.S. Cost-Saving Policy Forces New Kidney Transplant

By [KEVIN SACK](#)

SAN DIEGO — Melissa J. Whitaker has one very compelling reason to keep up with the health care legislation being written in Washington: her second transplanted kidney.

The story of Ms. Whitaker's two organ donations — the first from her mother and the second from her boyfriend — sheds light on a [Medicare](#) policy that is widely regarded as pound-foolish. Although the government regularly pays \$100,000 or more for kidney transplants, it stops paying for anti-rejection drugs after only 36 months.

The [health care bill](#) moving through the House of Representatives includes a little-noticed provision that would reverse the policy, but it is not clear whether the Senate will follow suit. The 36-month limit is one of several reimbursement anomalies — along with inadequate primary care payments and incentives that encourage unneeded care — that many in Congress hope to cure.

Ms. Whitaker, 31, who describes herself as “kind of a nerd,” has [Alport syndrome](#), a genetic disorder that caused [kidney failure](#) and significant [hearing loss](#) by the time she was 14. In 1997, after undergoing daily [dialysis](#) for five years, she received her first transplant. Most of the cost of the dialysis and the transplant, totaling hundreds of thousands of dollars, was absorbed by the federal Medicare program, which provides [broad coverage](#) for those with end-stage renal disease.

Despite that heavy investment, federal law limits Medicare reimbursement for the immunosuppressant drugs that transplant recipients must take for life, at costs of \$1,000 to \$3,000 a month.

Once Ms. Whitaker's Medicare expired, she faced periods without work and, more important, without group [health insurance](#), which disregards pre-existing conditions. Struggling financially, she soon found herself skipping doses of anti-rejection drugs.

By late 2003, her transplanted kidney had failed, and she returned to dialysis, covered by the government at \$9,300 a month, more than three times the cost of the pills. Then 15 months ago, Medicare paid for her second transplant — total charges, \$125,000 — and the 36-month clock began ticking again.

“If they had just paid for the pills, I'd still have my kidney,” said Ms. Whitaker, who shares an apartment in the La Jolla neighborhood with her boyfriend, Joseph D. Jamieson. “I'd be healthy, working and paying taxes.”

The Medicare program is not sure how many of the country's 100,000 transplant recipients are without insurance for their immunosuppressant drugs. Officials with the National Kidney Foundation said some dialysis patients never put themselves on transplant lists because they fear that they will not be able to afford the drugs.

Currently unemployed, Ms. Whitaker is nervous that in two years she will again find herself without health coverage. She and Mr. Jamieson, who have been together five years, said they would marry if necessary so he could insure her under the group policy provided by his employer, the drug manufacturer Pfizer. But nothing is guaranteed.

“If Joe were ever to lose his job or medical coverage, I do feel it would be possible for me to find myself without insurance again,” said Ms. Whitaker, who reads lips to compensate for her hearing loss. “I’m extremely nervous about whether I’m going to be able to afford my medications once my coverage runs out.”

Bills have been introduced in Congress since 2000 to lift the 36-month limit and extend coverage of immunosuppressant drugs indefinitely. They have never made it to a vote, largely because of the projected upfront cost; the [Congressional Budget Office estimates](#) that unlimited coverage would add \$100 million a year to the \$23 billion Medicare kidney program.

But the cost-benefit analysis would seem obvious. The most recent [report](#) from the United States Renal Data System found that Medicare spends an average of \$17,000 a year on care for [kidney transplant](#) recipients, most of it for anti-rejection drugs. That compares with \$71,000 a year for dialysis patients and \$106,000 for a transplant (including the first year of monitoring).

“It doesn’t make any sense at all,” Ms. Whitaker said. “Somebody’s not looking at the numbers.”

A provision to cover the drugs is in the sweeping House health care bill, which has cleared three committees. It is uncertain whether the Senate Finance Committee will include it in its bill.

Since 1973, end-stage renal disease has been the only condition specifically covered by Medicare regardless of age. In 1988, coverage was extended for 12 months to anti-rejection drugs, which had recently been developed. Congress gradually lengthened the cutoff to 36 months, and then in 2000 made the benefit unlimited for those who are at least 65 or disabled. The rationale for leaving out younger transplant recipients was simply that the money was not there, Congressional aides said.

Ms. Whitaker was married when her Medicare eligibility expired after her first transplant, and her husband was able to insure her under his group policy. They divorced in 2001, and she became uninsured until taking a job at Kinko’s that provided health benefits.

Her downward spiral began the day she awoke to find that her dog had used her [hearing aids](#) as a chew toy. She could not afford replacements and had to leave her job because she was unable to interact with customers.

She lived in Seattle for a while without electricity or hot water. The bank repossessed her car, and she filed for bankruptcy. Her grandmother eventually bought her new hearing aids, and she went back to work. But she was laid off a year later.

“That’s when I started stretching out the pills,” she said. “I’d take one in the morning and one at night, instead of two. Toward the end, I ran out of pills and was taking nothing for a couple of months. I figured I was young and could make it until I found insurance.”

She figured wrong. When she arrived at an emergency room, weak from weight loss and [anemia](#), her doctors told her they were surprised she was not in a [coma](#). The kidney, they said, had not been functioning at all.

“I felt really guilty because it was my mom’s kidney and I broke it,” Ms. Whitaker said.

Ms. Whitaker moved back to Southern California to live with her mother, and soon met Mr. Jamieson. He is seven years younger and, at 6-foot-8, stands 16 inches taller, but they had what Mr. Jamieson calls “a mutual dork synchronicity” (they share a passion for video games). He bought her a stuffed kidney, with a ureter nose, and almost immediately offered her one of his kidneys.

She declined. “I didn’t want to start dating somebody and steal his kidney,” she said. “That seemed kind of

rude.”

Several years later, she reversed course and accepted the transplant on June 10, 2008. She has suffered several minor rejection episodes, but lately has been feeling well.

The couple gets by on Mr. Jamieson’s paycheck and Ms. Whitaker’s [Social Security](#) benefits. With the help of financial aid, she recently completed two years at a community college and will soon start classes at the [University of California, San Diego](#). She said she hoped a degree would help her find a job with health coverage, perhaps as an addiction counselor.

But her bigger hope is that Congress will eliminate the 36-month limit so she can pursue any job, without concern for insurance.

“My whole life is dictated by my illness, and it’s such a waste,” Ms. Whitaker said. “If the government is going to spend all that money to help people get a kidney, they should help you keep it.”

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