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Transplants Cut, Arizona Is Challenged by Survivors

By **MARC LACEY**

PHOENIX — First, it was distraught patients awaiting organ transplants who protested Arizona's decision to no longer cover such operations under its [Medicaid](#) program.

Now, Arizonans who received such transplants, and are alive and well as a result of them, are questioning the data that lawmakers relied on to make their controversial benefit cuts.

"They say it's too expensive," said Star Boelter, 52, who had a [stem cell](#) transplant that was paid for by Arizona's Medicaid program in 2009 after suffering from leukemia. "Well, how much is life worth? They say most people die. Well, I'm alive because of my transplant."

When Arizona lawmakers voted last spring to cut some state-financed transplant coverage, they relied on data provided by state health officials showing that the procedures were rarely successful. But transplant experts and some patients who have undergone the now-discontinued procedures question the state's numbers.

For bone marrow transplants, the legislators were told that 13 of 14 patients covered by the state's Medicaid program who underwent that procedure died within six months. The 14th patient could not be tracked, state health officials told the Legislature, and might have died as well.

But Kim Marie Urick, a leukemia survivor, wants the state's leaders to know that she is able to ride her three horses outside Sedona and spend time with her husband and son thanks to a [bone marrow transplant](#) that Arizona's Medicaid program paid for on June 4, 2009.

“I was about five days away from dying,” she said in a telephone interview. “I essentially had no immune system. If it wasn’t for the bone marrow transplant, I wouldn’t be here right now.”

The cure rate for bone marrow transplants cited in the report to the Legislature was either zero or 7 percent, depending on whether that unidentified 14th patient lived. But transplant experts put the actual survival rate, based on national studies, at over 40 percent.

Dr. Jeffrey R. Schriber, medical director of the Blood and Marrow Transplant Program at Banner Good Samaritan Medical Center in Phoenix, has written to Gov. [Jan Brewer](#) and state lawmakers telling them that their decisions were based on incomplete data that gave the wrong picture. His data show the success rate for bone marrow transplants covered by Arizona’s Medicaid program at slightly higher than the national average. Of 20 operations performed at Banner in recent years, 9 patients have survived, he said.

State Representative John Kavanagh, a Republican and chairman of the House Appropriations Committee, has said that if new data was presented, he would be willing to reconsider at least some of the cuts to the Arizona Health Care Cost Containment System, as the Medicaid program is known, when the Legislature returns to session next month to tackle the state’s budget crisis.

But Ms. Brewer has not acknowledged that the cuts she signed into law might have been based on incomplete data. She [repeated the figure](#) that 13 out of 14 bone marrow transplant recipients died in Arizona while discussing the issue with Greta van Susteren on Fox News last week.

“Because Arizona has been hit with a devastating budget deficit, we have had to do some difficult decisions,” she said, adding later, “We have no other choices.”

But Democrats disagree, especially State Representative Anna Tovar, who underwent a bone marrow transplant herself a decade ago, although not as part of the state Medicaid plan. She has been among the most vocal critics of the transplant cuts, [calling for a special session](#) this month to reconsider the decision.

Ms. Tovar’s body rejected the bone marrow transplant in 2001, and she then underwent a stem cell transplant the next year. “I’m living proof that these transplants do work,” she said.

Ms. Urick, 53, still remembers when she learned that she was being considered for a transplant that might extend her life. "To be told there's a way you can live is one of the most wonderful things you can ever hear," she said. "I can't imagine what those who are waiting for transplants now and can't afford them are going through."

As for her, Ms. Urick said, "I plan on living another 20, 30 or 40 years."

Ms. Boelter, a massage therapist, is back to providing relief to others. "I'm working," she said. "I'm paying taxes, just as I've done for most of my life."

Another leukemia survivor, Michael Chessaek, 27, who underwent a bone marrow transplant in 2008, remains on disability but still credits the operation with allowing him to live.

"We send money all over the world to help people, and those who are suffering at home are not getting the help they need," said Mr. Chessaek, whose operation was covered under his private insurance coverage, which his mother supplemented with money from her retirement plan.

Bone marrow transplants are not the only ones in which legislators used questionable data to make their decision, transplant experts say. The American Society of Transplant Surgeons called Arizona's transplant cuts "decisions with no medical justification."

Liver transplants for those with [hepatitis C](#), which the state also discontinued, have a survival rate exceeding 80 percent after one year and 60 percent after five years, the transplant group said. Arizona's study of such procedures was far more pessimistic, saying such transplants "do not significantly affect the diseases they are intended to cure."

For lung transplants, the transplant society called them "life saving, not palliative," in response to the Arizona study, which labeled them "more palliative than curative."

James Healy, 25, a student at [Arizona State University](#), had a state-financed bone marrow transplant in 2009 and is back at school part time studying applied [psychology](#). "I'm well on my way to recovery," said Mr. Healy, who suffered from leukemia. "I've started school again, and I'm getting out and about. I've seen other people go through it, and I've gone through it. We're very much alive."

