

Help Eludes Leukemia Sufferer

Officials: Red Tape Blocking Funds for Marrow Transplant

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Brian Angel knows what a hole in a safety net looks like. He is falling through one.

The Albuquerque man has a rare form of leukemia. His only hope for a cure, according to his doctor, is a bone marrow transplant.

But Angel, 23, has no insurance to cover the cost of a transplant and no transplant center willing to perform the procedure without payment.

He gets federal disability payments that give him too much money — about \$550 a month — to qualify for the state Medicaid program, which covers medical bills for low-income people. And Medicare, which covers people under the federal disability program, doesn't kick in until 24 months after a person has been enrolled.

Angel's situation is not unique.

"This is a nationwide gap in coverage," said Charles Milligan, who heads the state's Medicaid program. Any correction would have to be made on the federal level, he added.

But some states do set their income guidelines high



PAT VASQUEZ-CUNNINGHAM/FOR THE JOURNAL

RARE DISEASE: Brian Angel, 23, right, endures a platelet transfusion last week while certified nurse's assistant Katie Rourke takes his vital signs.

enough to include such patients under the Medicaid umbrella, said Becky Thompson, a social worker with the Cancer Research and Treatment Center at the University of New Mexico.

Dr. Ian Rabinowitz, Angel's oncologist, wrote a letter

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along with clinical pharmacist Jim Krieger and 14 other clinical staffers from the cancer center at the University of New Mexico asking Rep. Heather Wilson for help in the case.

"We must have an adequate safety net program for young patients like Brian," the letter said.

Wilson, R-N.M., said her office staff is researching the issue.

"It seems like a Catch-22, if I understand the letter correctly," she said. "He's left uncovered for health care because of his health problem ...

"It doesn't make sense to me ... If this case is legitimate and it's a serious problem, we're trying to find out what can be done, whether it requires legislation or other action," she said.

Angel said he became ill around November 1997, when he had a cough that wouldn't go away and found himself getting cold and sleepy a lot. In January 1998, he said he had his spleen removed — it was enlarged — and was diagnosed with hypereosinophilia, a rare form of leukemia.

Since then, Angel said, he has had a few rounds of chemotherapy in the hospital and has chemotherapy pills he takes at home. One intensification of the disease resulted in rogue blood cells clustering in his joints, causing "immense pain" that required morphine treatment and left him unable to walk for about a week, Angel said. He gets blood transfusions a couple times a week to keep his disease in check.

Angel said he became too sick to

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DR. IAN RABINOWITZ,

BRIAN ANGEL'S ONCOLOGIST

keep working as a delivery driver, and so he applied for benefits from the federal Social Security program.

He was able to qualify for Medicaid when he was accepted into the federal Supplemental Security Income program, which is aimed at low-income people with disabilities.

Last summer, though, the Social Security system approved Angel for another program for disabled people, one that pays higher monthly benefits, Thompson said. That made him ineligible for Medicaid, but he can't get Medicare coverage under the federal disability program until he is enrolled for 24 months.

Angel gets \$546 per month. The ceiling under SSI that would make him eligible for Medicaid is \$520 per month.

Angel is getting some treatment under UNM Cares, a managed care program for the poor at University Hospital. Patients in the program are asked to make small co-payments for medical care.

Rabinowitz, who treats Angel for his cancer, said Angel has shown little response to the chemotherapy.

"We're just keeping him alive with blood platelet transfusions and supplemental chemotherapy. There's nothing else I can do for him," Rabinowitz said.

Rabinowitz said he would like to

have Angel evaluated for a bone marrow transplant

"His only chance for a cure — and it's a small chance — would be with a marrow transplant."

He stresses that a transplant is not a definite lifesaver.

"There's a good chance if he gets it that he will die as well," Rabinowitz said. "But if he doesn't get it, it's certain death."

No one in New Mexico does bone marrow transplants, Thompson said. She said she has called centers in Arizona, Colorado, California and Texas, and all refused to consider the procedure for someone without the means to pay for it.

"If you don't have a quarter million dollars up front, no transplant center will let you in the door," Rabinowitz said. People need private insurance or public assistance such as Medicaid to be accepted, he said.

Angel's story is not unique, Thompson said. Another New Mexico man, 42 and father of a 6-year-old son, died last month of leukemia, she said. He had a perfect bone marrow match as long as a year ago from a sibling who was willing to make the donation, Thompson said.

But he was unable to get the transplant because his disability payments were too high to qualify for Medicaid, and his Medicare had not kicked in, she said.

"There was nothing that could be done," Thompson said.

Bobby Wayne White, a 43-year-old Roswell man and father of five, is getting chemotherapy at University Hospital this week for his leukemia. His brother is a perfect match as a bone marrow donor, he said.

White, who worked all his life in the oil fields and didn't have private health insurance, got Medicaid when his illness made him quit working. Then he said he lost his Medicaid when he qualified for federal disability payments and won't become eligible for Medicare until next year.

"I'd rather have the insurance than the money," said White in a phone interview from his hospital bed. "But they won't budge. I can't do nothing. I just sit here and just hope."

He said his doctor told him that his chances don't look too good.

"They see you dying and they don't do nothing about it," White said of the bureaucracy that denies him insurance coverage. "My brother is 100-percent perfect (as a bone marrow match). All I need is insurance. Should I go up to somebody and say, 'Will you give me \$300,000?' It's just wrong."

He said he wants to stick around to help his wife raise their children, the youngest of whom is 7.

"It's unreal. It's horrible," Thompson said of the regulations depriving such people of health insurance. "I've worked here for four years. It's always been a problem."