

Arkansas denies life-extending drug to Medicaid recipients

Douglas Lyons
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Chloe Jones, a fourteen-year-old cystic fibrosis patient, has been denied the use of a life-extending drug called Kalydeco by the state of Arkansas.

Jones and two other patients filed a lawsuit in June alleging that Medicaid officials have barred them from using Kalydeco because of the cost. It also claims that state officials have infringed upon their civil rights under a federal law governing Medicaid.

Jones' cystic fibrosis forces her to wear an inflatable vest for three 45-minute treatments each day, putting pressure on her chest to loosen the buildup of mucus in her lungs.

Arkansas's Medicaid department had originally denied Jones's doctor's request for the drug in June 2012, saying that she had not taken the older, less-effective, medications for 12 months. Her family appealed the decision multiple times to no avail. Despite the state's official pretenses, it has now become apparent that the state is barring the use of the drug because of its cost—running around \$300,000 a year—which would be borne by the government-run healthcare plan for the poor, Medicaid.

Chloe told the *Wall Street Journal* in an interview, "They just don't want to pay for it. I feel like they don't care about what's wrong with me, that I'm not as important as everybody else." In fact, Chloe and the other patients meet the eligibility requirement stipulated by the Food and Drug Administration when it approved Kalydeco in 2012.

Matt Salo, executive director of the National Association of Medicaid Directors, told the *Wall Street Journal*, "We have this public health mentality that all people have to be cured no matter what the cost, and also let the innovators charge whatever they want. Those are fine theories independently, but when you combine them together in a finite budget environment,

it's not sustainable." An Arkansas spokeswoman reiterated the same sentiments: "Cost alone was not the determining factor, but how we will pay for it is something we must consider in advance as we are a state agency with limited funds."

27 percent of the population in Arkansas lives in poverty or near poverty, second only to Mississippi. Federal funds contributed more than two-thirds of Arkansas's \$4.79 billion Medicaid budget in 2013. Nationwide, more than 70 million low-income people are enrolled in Medicaid, which covers doctors' visits, prescription drugs, and additional medical services. An estimated 57% of Medicaid budgets are funded by the federal government, but states implement and enforce the program.

Chloe's doctor, Dennis Schellhase, told the *Wall Street Journal* that if she had been given Kalydeco in 2012 "we probably would've avoided most of the hospitalizations, if not all of them." Brian O'Sullivan, a cystic-fibrosis specialist at the University of Massachusetts Medical School, told the *Journal* that the "consensus among doctors is that all patients with the genetic defect should receive Kalydeco" because the drug is designed to stymie or diminish lung damage and extend patients' lifespan. Arkansas's denial is "unconscionable," he added.

The Arkansas case is not an isolated incident, but rather part of a trend that is becoming more pronounced. Recently, a new drug that cures hepatitis C, called Sovaldi, has been made available for patients, but in some states the criteria to receive it is when a patient is close to liver failure. For instance, Oregon only allows Medicaid to pay for the drug when the individual has irreversible liver damage. The state's Medicaid body has also proposed a recommendation that the state permanently exclude Sovaldi as an

approved medicine for Medicaid patients. The new drug costs \$84,000 for a 12-week-long supply.

The Affordable Care Act, or Obamacare, has likewise effectively barred certain expensive treatments for working-class people. Most of the least-expensive plans have a list of allowable drugs that the plan will partially cover. But any drugs outside the list, including those needed to treat chronic diseases, will be billed in full to patients.



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