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Insurance for Clinical Trial Care a State-by-State Battle

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Steffanie Collings' best chance for surviving a brain cancer recurrence in 2006 was a clinical trial offering a stem cell transplant. Her parents faced a common dilemma: The trial covered the cost of the transplant, but their insurance company denied subsequent coverage of routine care, deeming it part of experimental treatment.

Steffanie, 18, got the transplant, but her parents are left with health care bills totaling nearly half a million dollars. Now, Oklahoma legislators and advocates are pushing for passage of a state bill, called Steffanie's Law, which would require insurance carriers to provide coverage of routine costs associated with clinical trial participation.

Although treatment and lab work during a clinical trial are covered by the trial sponsor, the cost of subsequent routine care may be left to the patient. Nearly half the country has state laws requiring insurance carriers to cover routine care to patients in clinical trials, and Medicare patients have been covered since 2001.

Advocate Nancy Thomason, founder and president of the Oklahoma Brain Tumor Foundation, unsuccessfully pushed for a similar bill in 2001 after her son was denied coverage to participate in a clinical trial.

"It really limits the access to these clinical trials and these new agents coming out," Thomason says. "Patients are concerned about leaving their family in debt, and most of the time, they just won't do it."

Steffanie's Law will go before the full Oklahoma Senate for a vote in March. "I think we have a pretty good chance of getting it passed," says Thomason.