SANTA CRUZ

State passes legislation to provide hospice for children

BY MATT KING
SENTINEL STAFF WRITER

California is poised to become one of the first states in the country to offer end-of-life hospice care to kids, a development that health care advocates say will address a moral gap in children's medicine.

"Children who are very sick and dying don't have access to hospice services like adults do," said Lori Butterworth, a Soquel resident and co-founder of the Watsonville-based Children's Hospice and Palliative Care Coalition. "It is inhumane to ask a parent to give up on any opportunity to save their life or prolong their life."

Hospice provides some acute care and tries to keep patients comfortable in their final months of life. Hospice workers also help prepare patients dealing with terminal illnesses and their families for death.

Typically, private insurers and the state will pay for in-home and other hospice care only if a patient forgoes curative treatments and has six months or less to live. Federal law prohibits public funding of hospice care for children, but later this summer Gov. Arnold Schwarzenegger is expected to sign into law a bill that would authorize the state to apply for a federal waiver and pay for hospice care.

The waiver will take about a year to negotiate, but could expand coverage to children who continue to receive potential life-saving treatment. Butterworth said the federal government has agreed to approve a waiver similar to one in Florida.

"We will have a lot more flexibility about how we care for children who are very sick," she said. "We can care for children who are still getting chemotherapy. They don't have to be dying."

The bill, AB 1745, was written by Assemblywoman Wilma Chan, D-Oakland. It is named in honor of Nick Snow, a one-time Santa Cruz resident who recently died during surgery related to his recovery from neuroblastoma.

Snow was 16.

The Nick Snow bill unanimously passed the Assembly and Senate but must return to the Assembly to reconcile amendments.

Sabrina Lockhart, a Schwarzenegger spokeswoman, indicated the governor will sign the bill.

"We have worked closely with the bill's author and other stakeholders and we look forward to this legislation reaching the governor's desk," Lockhart said.

Contact Matt King at mking@santacruzsentinel.com.