



AB 1488– Sickle Cell Treatment Act

IN BRIEF

AB 1488 provides funding to provide rational care for persons who have sickle cell disease. Currently this underserved group have little resources for their care and as a result they are forced to use emergency rooms and hospitalization to provide primary care. This is the most expensive and the least effective way to provide care for a chronic illness. The goal of the funding will be coordination of care, increased utilization of resources and a reduction in overall cost of care.

BACKGROUND

Sickle cell disease affects approximately 7000 people in the State of California. It is an inherited disease that affects primarily African Americans and Hispanics, it is a lifelong disease that generally becomes medically more complex with age. For those with this disease the quality of life is poor related to the fact that there are few adult physicians specializing in sickle cell disease in the state (between 2 and 6 physicians). There is no coordination of care or resources within the state, there are no agreed upon standards of care within the state, the quality of care is substandard in many cases.

It has been known for decades that the care for children who have sickle cell disease is very good if they live near a sickle cell center and that the care for those over the age of eighteen is substandard across the state. Morbidity and mortality rise exponentially after the age of eighteen. The life expectancy has not changed since the 1980's and remains between 45 and 50 years for most.

Due to the lack of coordinated care young adults and older persons who have sickle cell disease disproportionately utilize emergency rooms and have high hospital admission rates and hospital readmission rates. The cost of emergency room visits and hospitalization alone is approximately 350 million dollars annually.

There are treatments for sickle cell disease, but due to

the lack of expertise and dedicated physicians few people who have sickle cell disease have access to these therapies.

SOLUTION

AB1488 provides a multitiered solution for the crisis of care experienced by those living with sickle cell disease. Poor care erodes their quality of life and is costs the State millions of dollars a year to provide uncoordinated and substandard care.

The bill proposes to create three to four sickle cell treatment centers in the State of California providing the state with Best Practice Guidelines to be used by all health care providers who care for patients with sickle cell disease. These centers will become resource centers to provide expertise and training for health care providers within the State.

AB 1488 increases reimbursement for the care of adults who have sickle cell commensurate with the complex care needed. Increased participation of internists and hematologists in the care sickle cell disease will lead to more people receiving appropriate therapy.

The bill also provides for support services for people with sickle cell disease to enable them to access the care centers and to help them adjust their lives to a chronic disease.

AB 1488 allows for genetic counseling for individuals affected both by sickle cell disease and sickle cell trait.

The bill proposes to case find and evaluate care for people who have sickle cell disease as a metric to show improvement in care and cost savings to the State.

SUPPORT

FOR MORE INFORMATION

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