

DEPARTMENT OF FINANCE BILL ANALYSIS

AMENDMENT DATE: 06/15/2012
POSITION: Oppose

BILL NUMBER: AB 2034
AUTHOR: Fuentes, Felipe

BILL SUMMARY: Medical care: genetically handicapping conditions.

This bill would direct the Department of Health Care Services (DHCS) to develop a plan for the continued operation of the Genetically Handicapped Person Program (GHPP) after the implementation of federal health care reform. Included in this plan would be strategies to (1) preserve services currently available under GHPP that may not be available under federal health care reform; (2) continuing coverage to populations not covered under federal health care reform, and (3) add amyotrophic lateral sclerosis (ALS) to the list of GHPP-eligible conditions.

FISCAL SUMMARY

According to DHCS, there would be ongoing increased state operations costs of \$133,000 annually (\$67,000 General Fund) for one Nurse Evaluator II to accommodate the GHPP program needs related to the addition of ALS to the list of GHPP-eligible conditions.

This bill could result in an increase of \$3.6 million to \$71.2 million total funds (\$1.3 million to \$26.0 million General Fund) in GHPP local assistance costs due to adding ALS to the list of GHPP-eligible conditions.

SUMMARY OF CHANGES

Amendments to this bill since our analysis of the March 29, 2012 version include the following which do not change our position:

- Drafting error corrected (bill now references Genetically Handicapped Persons Program instead of Genetically Handicapped Person's Program).
- Requires that any subsequent care model that may replace GHPP after the implementation of federal health care reform also address treatment of ALS.
- Deletes reference to the GHPP Advisory Committee.

COMMENTS

The Department of Finance is opposed to this bill for the following reasons:

- Though this bill would be effective January 1, 2013, GHPP enrollees will become eligible for commercial coverage through the California Health Benefits Exchange (Exchange) effective January 1, 2014 as federal health care reform prohibits denial of coverage based on pre-existing conditions. As such, it has limited short-term benefit and will ultimately be unnecessary.
- Addition of ALS to the list of GHPP-eligible conditions would likely result in increased General Fund costs to the state.

Analyst/Principal (0562) A.Bazos	Date	Program Budget Manager Ken DaRosa	Date
Department Deputy Director		Date	
Governor's Office:	By:	Date:	Position Approved _____ Position Disapproved _____
BILL ANALYSIS			Form DF-43 (Rev 03/95 Buff)

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COMMENTS (continued)

- The proposed plan to operate GHPP after implementation of federal health care reform is vague on specifics, such as the timeline for development of the plan.

A related bill, AB 1467 (Committee on Budget), the health budget trailer bill for this year which has been enrolled and is awaiting action by the Governor, repeals the Advisory Committee on GHPP.

ANALYSIS

1. Programmatic Analysis

GHPP provides comprehensive health care coverage for persons with specified genetic diseases including cystic fibrosis and hemophilia, chronic degenerative neurologic diseases including Huntington's Disease, and metabolic diseases including phenylketonuria. Hemophilia is the most common GHPP-eligible condition treated. There is no income limit for GHPP. Persons eligible for GHPP must reside in California, have a qualifying genetic disease and if under age 21, be financially ineligible for California Children's Services. Families of GHPP clients pay an enrollment fee based on the percentage of adjusted gross income relative to the federal poverty level.

ALS is a degenerative neurological disease that results in a gradual loss of control of voluntary muscle movement. It most commonly occurs in middle age. On average, patients die within two to five years from the time of diagnosis. There is no known prevention, no diagnostic test, no long-term treatment, and no known cure. It is estimated that 30,000 Americans have the disease at any given time. Under federal law, coverage through Medicare is available to many individuals with ALS upon qualifying for Social Security Disability Income (SSDI) via a special exception to the normal 24 month waiting period for Medicare benefits from the date of SSDI eligibility.

2. Fiscal Analysis

Based on information submitted by DHCS, there would be a potential need for one full time Nurse Evaluator II (or equivalent) to accommodate the GHPP program needs (case management, processing of treatment authorization requests, etc.) related to the addition of ALS to the list of GHPP-eligible conditions at an annual cost of \$133,000 total funds. These state operations costs assume a funding split of 50 percent General Fund and 50 percent Federal Trust Fund.

The estimated health care cost for each person with ALS varies from as low as \$10,000 during the first year to \$200,000 during the last year of life. Currently, there are approximately 300 diagnosed cases of ALS in California. The cost of providing care to these individuals once eligible for GHPP/Medi-Cal would range from an estimated \$3 million to \$60 million, depending on the stage of the disease. According to DHCS, as many as 56 new ALS cases could become eligible for GHPP annually. The estimated cost of providing care annually for 56 individuals would be an estimated \$0.6 million to \$11.2 million depending on the stage of the disease. Assuming an annual ALS GHPP caseload of 356, total increased costs could range from \$3.6 million to \$71.2 million. These costs are likely to be the maximum possible costs because it does not take into account cases covered by Medicare or private insurance. In such a case, private insurance would pay first, Medicare would pay second, and Medi-Cal would be the payer of last resort along with the state-only GHPP program.

The Medi-Cal program receives 50 percent of its funding from the General Fund. The state-only GHPP program receives all of its funding from the General Fund after enrollment fees, blood factor drug rebates, and any available funding from federal Safety Net Care Pool Funds related to the Bridge to Reform Medi-Cal Waiver is taken into account. Thus, while an exact fiscal impact to the state is

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ANALYSIS (continued)

difficult to estimate, assuming the current caseload split between the Medi-Cal and state-only GHPP programs (46 and 54 percent respectively), this proposal could result in a General Fund increase of \$1.3 million to \$26 million. It is likely these costs would rise over time with growth in the ALS portion of the GHPP caseload.

Code/Department Agency or Revenue Type	SO	(Fiscal Impact by Fiscal Year)						Fund Code
	LA	(Dollars in Thousands)						
	CO	PROP						
	RV	98	FC	2011-2012	FC	2012-2013	FC	2013-2014
4260/Hlth Care	SO	No	A	--	C	66	C	66 0001
4260/Hlth Care	SO	No	A	--	C	67	C	67 0890
4260/Hlth Care	LA	No	A	--	C	1,300-26,000	C	1,300-26,000 0001
4260/Hlth Care	LA	No	A	--	C	2,300-45,200	C	2,300-45,200 0494
<u>Fund Code</u>	<u>Title</u>							
0001	General Fund							
0494	Other - Unallocated Special Funds							
0890	Trust Fund, Federal							