

**ASSEMBLY BILL**

**No. 2034**

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**Introduced by Assembly Member Fuentes  
(Principal coauthor: Assembly Member Bonilla)**

February 23, 2012

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An act to amend Section 125130 of the Health and Safety Code, relating to health services.

LEGISLATIVE COUNSEL'S DIGEST

AB 2034, as introduced, Fuentes. Medical care: genetically handicapping conditions.

Existing law, the Holden-Moscone-Garamendi Genetically Handicapped Person's Program, requires the Director of Health Care Services to establish and administer a program for the medical care of persons with specified genetically handicapping conditions and for persons with specified hereditary metabolic disorders. That law also requires the program to provide access to social support services that may help ameliorate problems that are attendant to genetically handicapping conditions. Existing law authorizes the director to expand the list of genetically handicapping conditions.

This bill would add familial amyotrophic lateral sclerosis to the list of genetically handicapping conditions covered under the act.

Vote: majority. Appropriation: no. Fiscal committee: yes. State-mandated local program: no.

*The people of the State of California do enact as follows:*

- 1 SECTION 1. Section 125130 of the Health and Safety Code
- 2 is amended to read:

1 125130. The Director of Health *Care* Services shall establish  
2 and administer a program for the medical care of persons with  
3 genetically handicapping conditions, including cystic fibrosis,  
4 hemophilia, sickle cell disease, Huntington’s disease, Friedreich’s  
5 Ataxia, Joseph’s disease, Von Hippel-Landau syndrome, *familial*  
6 *amyotrophic lateral sclerosis*, and the following hereditary  
7 metabolic disorders: phenylketonuria, homocystinuria, branched  
8 chain amino acidurias, disorders of propionate and methylmalonate  
9 metabolism, urea cycle disorders, hereditary orotic aciduria,  
10 Wilson’s Disease, galactosemia, disorders of lactate and pyruvate  
11 metabolism, tyrosinemia, hyperornithinemia, and other genetic  
12 organic acidemias that require specialized treatment or service  
13 available from only a limited number of program-approved sources.

14 The program shall also provide access to social support services,  
15 that may help ameliorate the physical, psychological, and economic  
16 problems attendant to genetically handicapping conditions, in order  
17 that the genetically handicapped person may function at an optimal  
18 level commensurate with the degree of impairment.

19 The medical and social support services may be obtained through  
20 physicians and surgeons, genetically handicapped person’s program  
21 specialized centers, and other providers that qualify pursuant to  
22 the regulations of the department to provide the services. “Medical  
23 care,” as used in this section, is limited to noncustodial medical  
24 and support services.

25 The director, with the guidance of the Advisory Committee on  
26 Genetically Handicapped Person’s Program, may, by regulation,  
27 expand the list of genetically handicapping conditions covered  
28 under this article. The director shall adopt regulations that are  
29 necessary for the implementation of this article. The director, with  
30 the approval of the advisory committee, shall establish priorities  
31 for the use of funds and provision of services under this article.