

AMENDED IN ASSEMBLY MARCH 29, 2012

AMENDED IN ASSEMBLY MARCH 14, 2012

CALIFORNIA LEGISLATURE—2011–12 REGULAR SESSION

ASSEMBLY BILL

No. 2034

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

February 23, 2012

An act to ~~amend Section 125130 of~~ *add Section 125191.5* to the Health and Safety Code, relating to health services, ~~and making an appropriation therefor.~~

LEGISLATIVE COUNSEL'S DIGEST

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

Existing law, the Holden-Moscone-Garamendi Genetically Handicapped Person's Program (*GHPP*), 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.~~

Existing law, the federal Patient Protection and Affordable Care Act (PPACA), among other provisions, reformed certain aspects of the private health insurance industry and public health insurance programs.

~~This bill would add genetic amyotrophic lateral sclerosis to the list of genetically handicapping conditions covered under the program~~

require the State Department of Health Care Services, in consultation with designated entities, to develop a plan for the administration of the GHPP after the implementation of the PPACA. This bill would require the plan to address, among other things, preservation of the availability of wrap-around services that would otherwise not be available through the PPACA and the addition of genetic amyotrophic lateral sclerosis to the list of conditions covered under the GHPP.

~~Existing law establishes the Children’s Medical Services Rebate Fund, which is continuously appropriated to the State Department of Health Care Services to cover costs related to services, and the administration of services, provided through the program. Moneys from rebates for the delivery of health care and specified products for clients enrolled into the program are required to be deposited into the fund.~~

~~To the extent that expanding the clients served by the program would increase the moneys deposited into the fund, this bill would make an appropriation.~~

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

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

- 1 SECTION 1. Section 125191.5 is added to the Health and
- 2 Safety Code, to read:
- 3 125191.5. (a) The department, in consultation with the
- 4 California Health Benefit Exchange and the Advisory Committee
- 5 on Genetically Handicapped Person’s Program, shall develop a
- 6 plan for the continued operation of the Genetically Handicapped
- 7 Person’s Program after implementation of the federal Patient
- 8 Protection and Affordable Care Act. The plan shall address all of
- 9 the following:
- 10 (1) Preserving the availability of wrap-around services that will
- 11 not otherwise be available after implementation of the federal
- 12 Patient Protection and Affordable Care Act (Public Law 111-148).
- 13 (2) Continued coverage for any residual services and
- 14 populations.
- 15 (3) Adding genetic amyotrophic lateral sclerosis (ALS) to the
- 16 Genetically Handicapped Person’s Program list of conditions, as
- 17 described in Section 125130. The care and treatment for genetic
- 18 ALS under the Genetically Handicapped Person’s Program shall
- 19 be consistent with the principles described in Section 104323.

1 (b) *As an alternative to consulting with the Advisory Committee*
2 *on Genetically Handicapped Person's Program, in developing the*
3 *plan described in subdivision (a), the department may consult with*
4 *stakeholders, representatives of Genetically Handicapped Person's*
5 *Program providers, persons with genetically handicapped*
6 *conditions, special care centers, genetic disease medical experts,*
7 *and other interested persons.*

8 SECTION 1. ~~Section 125130 of the Health and Safety Code~~
9 ~~is amended to read:~~

10 ~~125130. The Director of Health Care Services shall establish~~
11 ~~and administer a program for the medical care of persons with~~
12 ~~genetically handicapping conditions, including cystic fibrosis,~~
13 ~~hemophilia, sickle cell disease, Huntington's disease, Friedreich's~~
14 ~~Ataxia, Joseph's disease, Von Hippel-Landau syndrome, genetic~~
15 ~~amyotrophic lateral sclerosis, and the following hereditary~~
16 ~~metabolic disorders: phenylketonuria, homocystinuria, branched~~
17 ~~chain amino acidurias, disorders of propionate and methylmalonate~~
18 ~~metabolism, urea cycle disorders, hereditary orotic aciduria,~~
19 ~~Wilson's Disease, galactosemia, disorders of lactate and pyruvate~~
20 ~~metabolism, tyrosinemia, hyperornithinemia, and other genetic~~
21 ~~organic acidemias that require specialized treatment or service~~
22 ~~available from only a limited number of program-approved sources.~~

23 ~~The program shall also provide access to social support services,~~
24 ~~that may help ameliorate the physical, psychological, and economic~~
25 ~~problems attendant to genetically handicapping conditions, in order~~
26 ~~that the genetically handicapped person may function at an optimal~~
27 ~~level commensurate with the degree of impairment.~~

28 ~~The medical and social support services may be obtained through~~
29 ~~physicians and surgeons, genetically handicapped person's program~~
30 ~~specialized centers, and other providers that qualify pursuant to~~
31 ~~the regulations of the department to provide the services. "Medical~~
32 ~~care," as used in this section, is limited to noncustodial medical~~
33 ~~and support services.~~

34 ~~The director, with the guidance of the Advisory Committee on~~
35 ~~Genetically Handicapped Person's Program, may, by regulation,~~
36 ~~expand the list of genetically handicapping conditions covered~~
37 ~~under this article. The director shall adopt regulations that are~~
38 ~~necessary for the implementation of this article. The director, with~~

- 1 ~~the approval of the advisory committee, shall establish priorities~~
- 2 ~~for the use of funds and provision of services under this article.~~

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