

AMENDED IN SENATE JUNE 29, 2000
AMENDED IN SENATE JUNE 14, 2000
AMENDED IN ASSEMBLY APRIL 24, 2000
AMENDED IN ASSEMBLY APRIL 5, 2000

CALIFORNIA LEGISLATURE—1999–2000 REGULAR SESSION

ASSEMBLY BILL

No. 2427

Introduced by Assembly Member Kuehl
(Coauthors: Assembly Members Jackson and Knox)
(Coauthor: Senator Perata)

February 24, 2000

An act to amend Sections 124975 and 125001 of, and to repeal Section 125005 of, the Health and Safety Code, relating to genetic testing, and making an appropriation therefor.

LEGISLATIVE COUNSEL'S DIGEST

AB 2427, as amended, Kuehl. Genetic diseases: genetic screening.

The Hereditary Disorders Act requires the State Department of Health Services to establish a program to provide genetic screening services. The department is required to charge a fee and deposit the fee into the Genetic Disease Testing Fund, which is continuously appropriated for certain purposes.

This bill would provide that fees would be established and adjusted by the Director of Health Services. This bill would expand the purposes for which the moneys in the fund may

be expended, thereby making an appropriation. This bill would also state the Legislature's findings regarding the maintenance of genetic screening programs.

Existing law requires the department to establish a program for genetic disease testing and authorizes the department to provide facilities to and contract with qualified laboratories. Existing law requires the department to charge a fee for additional screening and lists the additional genetic conditions that may be tested for under the program.

This bill would instead require the department to establish a program for the development and evaluation of genetic disease testing. It would permit the department to charge a fee for developmental screening and would delete the list of genetic conditions that may be tested for under the program.

Existing law requires the department to report to the Legislature regarding program progress by June 30, 2000.

This bill would require the department to report to the Legislature on or before January 1, 2002. This bill would also appropriate \$3,900,000 to the department from the Genetic Disease Testing Fund to fund the cost of the trial of the program and a followup report.

Vote: $\frac{2}{3}$. Appropriation: yes. Fiscal committee: yes. State-mandated local program: no.

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

1 SECTION 1. Section 124975 of the Health and Safety
 2 Code is amended to read:
 3 124975. The Legislature hereby finds and declares
 4 that:
 5 (a) Each person in the State of California is entitled to
 6 health care commensurate with his or her health care
 7 needs, and to protection from inadequate health services
 8 not in the person's best interests.
 9 (b) Hereditary disorders, such as sickle cell anemia,
 10 cystic fibrosis, and hemophilia, are often costly, tragic,
 11 and sometimes deadly burdens to the health and
 12 well-being of the citizens of this state.
 13 (c) Detection through screening of hereditary
 14 disorders can lead to the alleviation of the disability of



1 some hereditary disorders and contribute to the further
2 understanding and accumulation of medical knowledge
3 about hereditary disorders that may lead to their eventual
4 alleviation or cure.

5 (d) There are different severities of hereditary
6 disorders, that some hereditary disorders have little effect
7 on the normal functioning of individuals, and that some
8 hereditary disorders may be wholly or partially alleviated
9 through medical intervention and treatment.

10 (e) All or most persons are carriers of some deleterious
11 recessive genes that may be transmitted through the
12 hereditary process, and that the health of carriers of
13 hereditary disorders is substantially unaffected by that
14 fact.

15 (f) Carriers of most deleterious genes should not be
16 stigmatized and should not be discriminated against by
17 any person within the State of California.

18 (g) Specific legislation designed to alleviate the
19 problems associated with specific hereditary disorders
20 may tend to be inflexible in the face of rapidly expanding
21 medical knowledge, underscoring the need for flexible
22 approaches to coping with genetic problems.

23 (h) State policy regarding hereditary disorders should
24 be made with full public knowledge, in light of expert
25 opinion and should be constantly reviewed to consider
26 changing medical knowledge and ensure full public
27 protection.

28 (i) The extremely personal decision to bear children
29 should remain the free choice and responsibility of the
30 individual, and should not be restricted by the state.

31 (j) Participation of persons in hereditary disorders
32 programs in the State of California should be wholly
33 voluntary, except for initial screening for
34 phenylketonuria (PKU) and other genetic disorders
35 treatable through the California newborn screening
36 program. All information obtained from persons involved
37 in hereditary disorders programs in the state should be
38 held strictly confidential.

39 (k) In order to minimize the possibility for the
40 reoccurrence of abuse of genetic intervention in



1 hereditary disorders programs, all programs offering
2 screening programs for ~~heredity~~ *hereditary* disorders
3 shall comply with the principles established in the
4 Hereditary Disorders Act (Section 27). The Legislature
5 finds it necessary to establish a uniform statewide policy
6 for the screening for ~~heredity~~ *hereditary* disorders in the
7 State of California.

8 (l) The Genetic Disease Testing Fund is continued in
9 existence as a special fund in the State Treasury. All
10 moneys collected by the department for activities
11 conducted as authorized in this chapter shall be deposited
12 in the Genetic Disease Testing Fund which,
13 notwithstanding Section 13340 of the Government Code,
14 is continuously appropriated to the department to carry
15 out the purposes of this chapter.

16 (m) It is the intent of the Legislature that, unless
17 otherwise specified, the program carried out pursuant to
18 this chapter be fully supported from fees collected for
19 services provided by the program.

20 (n) The department shall charge a fee *to all payers* for
21 any tests or activities performed pursuant to this chapter.
22 The amount of the fee shall be established by regulation
23 and periodically adjusted by the director in order to meet
24 the costs of this chapter. Notwithstanding any other
25 provision of law, any fees charged for screening and
26 followup services provided to Medi-Cal eligible persons,
27 health care service plan enrollees, or persons covered by
28 disability insurance policies, shall be paid in full directly
29 to the Genetic Disease Testing Fund. *A hospital shall not*
30 *be charged a fee for any test or activity performed*
31 *pursuant to this chapter.*

32 (o) (1) The Legislature finds that timely
33 implementation of changes in genetic screening
34 programs and continuous maintenance of quality
35 statewide services requires expeditious regulatory and
36 administrative procedures, including policies and
37 procedures developed pursuant to Sections 12101 and
38 12102 of the Public Contract Code or Division 25.2
39 (commencing with Section 38070) of the Health and
40 Safety Code, to obtain the most cost-effective electronic



1 data processing, hardware, software services, testing
2 equipment, testing services, and followup contracts.

3 (2) The expenditure of funds from the Genetic
4 Disease Testing Fund for these purposes shall not be
5 subject to Section 12113.5 of, and Chapter 2 (commencing
6 with Section 10290) of Part 2 of Division 2 of, the Public
7 Contract Code. The department shall provide the
8 Department of Finance with documentation that
9 equipment and services have been obtained at the lowest
10 cost consistent with technical requirements for a
11 comprehensive high-quality program.

12 SEC. 2. Section 125001 of the Health and Safety Code
13 is amended to read:

14 125001. (a) The Legislature finds and declares all of
15 the following:

16 (1) California requires testing at birth for certain
17 genetic diseases or conditions.

18 (2) Technology called tandem mass spectography is
19 now available that would permit testing for many more
20 genetic diseases or conditions.

21 (3) Many of the additional tests can be made from the
22 same blood sample at costs of between eighteen dollars
23 (\$18) and twenty dollars (\$20).

24 (4) It is the intent of the Legislature that a program for
25 testing services and training be initiated as expeditiously
26 as possible utilizing laboratory services experienced in
27 tandem mass spectography.

28 (b) The department shall establish a program for the
29 development and evaluation of genetic disease testing,
30 and may provide laboratory testing facilities or make
31 grants to, contract with, or make payments to, any
32 laboratory that it deems qualified to conduct tandem
33 mass spectrometry testing or with any metabolic
34 specialty clinic to provide necessary treatment with
35 qualified specialists. The program shall provide genetic
36 screening and followup services for persons who elect to
37 have the additional screening.

38 (c) The one-time sum of three million nine hundred
39 thousand dollars (\$3,900,000) is appropriated to the
40 department from the Genetic Disease Testing Fund in



1 order to support the cost of the trial of the program and
2 a followup report. It is the intent of the Legislature that
3 no additional fees be charged to patients for additional
4 genetic screening provided through tandem mass
5 spectrometry in the trial of the program.

6 (d) The department shall report to the Legislature
7 regarding the progress of the program on or before
8 January 1, 2002. The report shall include the costs for
9 screening, followup, and treatment as compared to costs
10 and morbidity averted for each condition tested for in the
11 program.

12 SEC. 3. Section 125005 of the Health and Safety Code
13 is repealed.

