

Introduced by Senator SteinbergFebruary 26, 2009

An act to amend Section 104323 of, and to add Sections 104323.1, 104323.2, and 104323.3 to, the Health and Safety Code, relating to public health.

LEGISLATIVE COUNSEL'S DIGEST

SB 513, as introduced, Steinberg. Amyotrophic lateral sclerosis.

Existing law provides for programs administered by the State Department of Public Health for the prevention and treatment of various diseases. Existing law establishes the ALS/Lou Gehrig's Disease Research Fund and provides for the deposit of voluntary taxpayer contributions to be used by the department to provide research grants to develop and advance the understanding, techniques, and modalities effective in the prevention, treatment, and cure of ALS.

This bill would request that the Regents of the University of California establish and administer the California ALS Disease Team with the goal of promoting and conducting scientific research on ALS and developing effective treatments and diagnostics.

This bill would require the Secretary of California Health and Human Services to be responsible for oversight and coordination of programs serving people with ALS and their families, would require the secretary to establish an ALS Advisory Committee, and would set forth the membership and duties of the committee.

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. The Legislature finds and declares all of the
2 following:

3 (a) The State of California supports the expansion of scientific
4 research on amyotrophic lateral sclerosis (ALS), commonly known
5 as Lou Gehrig’s Disease, and seeks to understand the impact ALS
6 has on veterans, health, and social services.

7 (b) To better serve ALS patients, it is necessary to build upon
8 existing research and to develop research-based information to
9 guide effective medical and social service interventions for this
10 patient population and to inform state policymakers regarding
11 health, social, and veterans programs available to these patients.

12 (c) An urgency exists in discovering new treatments and a
13 potential cure for ALS, as it is a fatal, degenerative, neurological
14 disease, which, on average, takes the life of patients two to five
15 years after diagnosis. It has been over 150 years since the scientific
16 community recognized ALS. Since then, only one pharmaceutical
17 treatment has become available. The benefit of this treatment is
18 limited, as it only works for some patients and, at best, offers only
19 a few additional months of life.

20 (d) The State of California seeks to help address the staggering
21 need for research by establishing the California ALS Disease Team.
22 The team-based approach encourages early consultation and
23 cooperation among researchers of diverse skills and expertise. This
24 approach has the potential to advance therapies into the clinic more
25 rapidly, therefore helping address the urgency of the needs of ALS
26 patients.

27 SEC. 2. Section 104323 of the Health and Safety Code is
28 amended to read:

29 104323. ~~The~~ (a) *For the purposes of this chapter “ALS” or*
30 *“Lou Gehrig’s disease” means Amyotrophic Lateral Sclerosis.*

31 (b) *The Legislature finds and declares all of the following:*

32 (a)

33 (1) *Amyotrophic Lateral Sclerosis (ALS), more commonly*
34 *known as Lou Gehrig’s disease, is a degenerative disease of the*
35 *motor nerves that causes progressive weakness of all voluntary*
36 *muscles. People with ALS become unable to move, swallow, speak,*
37 *and breathe without assistance, usually remaining fully aware of*
38 *what is happening to them and to their families.*

1 ~~(b)~~

2 (2) ALS is a fatal disease. Most ALS patients die within two to
3 five years of symptom onset. Every 90 minutes someone is
4 diagnosed with ALS and every 90 minutes someone dies of the
5 disease. ALS knows no racial, ethnic, or socioeconomic boundaries,
6 often striking people at midlife and at the height of family and
7 financial responsibilities.

8 ~~(c)~~

9 (3) The devastating physical, emotional, and financial effects
10 caused by the progression of ALS and the 24 hour a day, seven
11 day a week caregiving required impacts not only the patient, but
12 the entire family. ALS is a family disease.

13 ~~(d)~~

14 (4) For many patients, the one drug approved by the federal
15 Food and Drug Administration for the treatment of ALS shows
16 little, if any, efficacy in slowing the progression of the disease. As
17 a result, the focus of intervention for ALS patients is managing
18 the effects of the disease progression. Research has shown that
19 aggressive multidisciplinary care, provided within a collaborative
20 environment, can extend a patient's life, reduce hospital
21 admissions, and improve the quality of life for the patient and
22 family. Ultimately, though, more research is needed to find an
23 effective treatment and cure for ALS.

24 ~~(e)~~

25 (5) To significantly extend and improve the quality of life of
26 people living with ALS, the state recognizes the need for the
27 California System of Care for ALS Patients model based upon the
28 principles described in subdivision (f).

29 ~~(f)~~

30 (6) According to the American Academy of Neurology (AAN),
31 the mainstay of treatment for ALS patients is symptom
32 management. As a result, the AAN has established a practice
33 parameter for the care of ALS patients. These guidelines establish
34 a foundation on which to develop a system of care that enables the
35 delivery of a comprehensive array of services critical to the care
36 of ALS patients and their families. The AAN sets this foundation
37 in their four principles of ALS management summarized as
38 follows:

39 ~~(1)~~

1 (A) High priority should be placed on patient self-determination
2 and the delivery of both information and care must take into
3 consideration the cultural and psychosocial context of the patient
4 and family.

5 ~~(2)~~

6 (B) Patients and families need information that is timed
7 appropriately for decisionmaking.

8 ~~(3)~~

9 (C) The physician, in conjunction with other health care
10 professionals, should address the full continuum of care for the
11 patient with ALS.

12 ~~(4)~~

13 (D) Discussions regarding advance directives should be
14 introduced and periodically reevaluated to ensure that ALS patients
15 and their families understand the issues to be faced in the terminal
16 phase of the disease.

17 ~~(g)~~

18 (7) The services described in subdivision ~~(f)~~ (g), when delivered
19 through a highly coordinated effort, form a model program
20 designed to provide the highest level of care available for the
21 successful management of the needs of ALS patients and their
22 families.

23 ~~(h)~~

24 (8) ALS Association Certified Centers (centers) are a vehicle
25 for state-of-the-art multidisciplinary and interdisciplinary care and
26 management of ALS. The centers reflect four main objectives:

27 ~~(1)~~

28 (A) The involvement of all necessary health care disciplines in
29 the care of the ALS patient and his or her family.

30 ~~(2)~~

31 (B) The offering of multidisciplinary and interdisciplinary care,
32 regardless of the ability to pay.

33 ~~(3)~~

34 (C) Collaborative work among centers to enhance ALS patient
35 care techniques.

36 ~~(i)~~

37 (9) Centers provide a one-stop shop at which the patient and
38 family have access to a team of health care professionals from
39 every specialty area that they may need during the progression of
40 ALS. Each professional is an expert in ALS as well as his or her

1 own field. The team that assesses and treats patients during their
2 visits to a center includes individuals in all of the following
3 specialty areas:

4 ~~(1)~~

5 (A) Physical therapy.

6 ~~(2)~~

7 (B) Occupational therapy.

8 ~~(3)~~

9 (C) Respiratory therapy.

10 ~~(4)~~

11 (D) Nursing.

12 ~~(5)~~

13 (E) Registered dietician services.

14 ~~(6)~~

15 (F) Psychology or psychiatry.

16 ~~(7)~~

17 (G) Speech and language pathology.

18 ~~(8)~~

19 (H) Medical social work service.

20 ~~(j)~~

21 (10) An ALS Association Certified Center is a “specialty care
22 center” for the purposes of Section 1374.16.

23 SEC. 3. Section 104323.1 is added to the Health and Safety
24 Code, to read:

25 104323.1. (a) The Legislature hereby requests that the Regents
26 of the University of California establish and administer the
27 California ALS Disease Team within the University of California.

28 (b) The goal of the team is to promote and conduct scientific
29 research on ALS and to develop effective treatments and
30 diagnostics.

31 (c) The team is to be comprised of basic, translational, and
32 clinical scientists.

33 (d) The team may involve interinstitutional collaborations.

34 SEC. 4. Section 104323.2 is added to the Health and Safety
35 Code, to read:

36 104323.2. The Secretary of California Health and Human
37 Services shall be responsible for the oversight and coordination
38 of programs serving people diagnosed with amyotrophic lateral
39 sclerosis (ALS) and their families. This responsibility shall include,
40 but need not be limited to:

1 (a) State level support and assistance to all programs within the
2 Health and Human Services Agency and member departments
3 developed for this target population.

4 (b) Establishment of the ALS Advisory Committee.

5 (c) Review of the recommendations made by the ALS Advisory
6 Committee and subsequent state plans.

7 SEC. 5. Section 104323.3 is added to the Health and Safety
8 Code, to read:

9 104323.3. (a) The Secretary of California Health and Human
10 Services shall establish an ALS Advisory Committee consisting
11 of 14 members selected as follows:

12 (1) One representative of the field of academic medical research.

13 (2) One representative of the field of social services.

14 (3) Two representatives of the field of neurological medicine.

15 (4) Two representatives of the ALS Centers of Excellence.

16 (5) Two representatives of the ALS patient population.

17 (6) One representative of families of persons suffering from
18 ALS.

19 (7) One representative of the California ALS Disease Team.

20 (8) Two representatives of California ALS Association Chapters.

21 (9) One representative of veterans with ALS.

22 (10) The Secretary of California Health and Human Services
23 or his or her designee.

24 (b) Members shall serve at the pleasure of the Secretary of
25 California Health and Human Services. The secretary may establish
26 fixed terms for advisory committee membership. For purposes of
27 continuity, those terms shall be staggered.

28 (c) Members shall serve without compensation.

29 (d) The ALS Advisory Committee shall do all of the following:

30 (1) Appoint a chairperson and vice chairperson.

31 (2) Meet quarterly.

32 (3) Provide ongoing advice and assistance to the Governor and
33 the Legislature as to the program needs and priorities of the
34 targeted population.

35 (4) Provide planning support to the Governor and the Legislature
36 by providing a review of current available services, the gaps in
37 those services, and how the state can improve those services.

38 (e) The ALS Advisory Committee shall do all of the following
39 when making policy and plan recommendations:

- 1 (1) Consult with a broad range of stakeholders, including, but
2 not limited to, people diagnosed with ALS, family caregivers,
3 community-based and institutional providers, ALS disease
4 researchers and academicians, professional caregivers, the
5 California ALS Association Chapters, nonemergency medical
6 transporters, the State Department of Health Care Services, the
7 State Department of Social Services, the Department of Veterans
8 Affairs, and other state entities.
- 9 (2) Consider the difficulty that mobility and transportation play
10 in restricting or limiting an ALS patient's access to care.
- 11 (3) Review current state policies and practices concerning, and
12 treatment related to, ALS and develop recommendations.
- 13 (4) Review community-based support for ALS patients and
14 suggest how the state may partner with community-based
15 organizations to improve patient care.
- 16 (5) Review ALS case management practices and develop a
17 model that can be disseminated to state agencies and
18 community-based groups.
- 19 (6) Develop a mechanism to inform ALS disease advocacy
20 groups about state programs and services available to their patient
21 populations.
- 22 (7) Create a clearinghouse of information on research findings.
- 23 (8) Provide the Legislature with a report containing a review of
24 state policies and procedures concerning the care, treatment, and
25 services for ALS patients and offer specified recommendations
26 relating to the improvement of care for those patients in the state.
- 27 (f) All meetings of the advisory committee, and any of its
28 subcommittees, shall be open to the public and adequate notice
29 shall be provided in accordance with Article 9 (commencing with
30 Section 11120) of Chapter 1 of Part 1 of Division 3 of Title 2 of
31 the Government Code.