Up^ Add To My Favorites

HEALTH AND SAFETY CODE - HSC

DIVISION 106. PERSONAL HEALTH CARE (INCLUDING MATERNAL, CHILD, AND ADOLESCENT) [123100 - 125850] *(Division 106 added by Stats. 1995, Ch. 415, Sec. 8.)*

PART 5. HEREDITARY DISEASES/CONGENITAL DEFECTS [124975 - 125292.10] *(Part 5 added by Stats. 1995, Ch. 415, Sec. 8.)*

CHAPTER 2. Genetic Disease Services [125125 - 125286.35] *(Chapter 2 added by Stats. 1995, Ch. 415, Sec. 8.)*

ARTICLE 3. Huntington’s Disease Research and Workshop Grants [125225 - 125250] *(Article 3 added by Stats. 1995, Ch. 415, Sec. 8.)*

125225. The Legislature hereby finds and declares that:

(a) Huntington’s disease is a chronic progressive inherited disorder of the central nervous system.

(b) The constellation of mental and physical symptoms, the insidious onset of the disorder, and the torment of those at-risk, waiting throughout their lives to learn if they have been spared, conspire to make “Huntington’s disease one of the most diabolical diseases known to man.” Each child of a patient with Huntington’s disease has a 50/50 chance of getting the disease.

(c) Males, females, and all ethnic groups may be affected and there is no effective treatment or cure. Because so little is known about the disease, many people are misdiagnosed and mistreated.

(d) The suicide rate among Huntington’s disease patients is estimated to be seven times the national rate.

(e) The advancement of scientific knowledge about Huntington’s disease, that, because of its extraordinary range of symptoms, serves as an excellent prototype for other major chronic genetic, neurologic, and psychiatric illnesses and diseases of aging, such as epilepsy, muscular dystrophy, and Parkinson’s disease, will reveal fundamental scientific information that may lead to treatment, prevention, and ultimately a cure for an array of inherited disorders that affect millions.

(Added by Stats. 1995, Ch. 415, Sec. 8. Effective January 1, 1996.)

125230. The director may establish any rules or criteria for grants under this article as the director deems necessary.

(Added by Stats. 1995, Ch. 415, Sec. 8. Effective January 1, 1996.)

125235. There is hereby created a Scientific Advisory Review Committee. The membership of the committee shall be composed of 11 members who shall be representatives from each of the following:

(a) Two from the University of California.

(b) One from Stanford University.

(c) One from the California Institute of Technology.

(d) One from the Hereditary Disease Foundation.

(e) One from the City of Hope.

(f) One from the Health and Welfare Agency appointed by the Secretary of the Health and Welfare Agency.

(g) One appointed by the Speaker of the Assembly.

(h) One appointed by the President pro Tempore of the California Senate.

(i) One from the National Huntington’s Disease Association.

(j) One from the Committee to Combat Huntington’s Disease.

Except as otherwise provided in this section, members of the committee shall be appointed by the director, who shall make the appointments based upon recommendations from the entity or organization represented.

The members of the committee shall serve at the pleasure of the appointing power. The members of the committee shall serve without compensation, but shall be reimbursed for necessary and travel expenses incurred in the performance of the duties on the committee.

The Scientific Advisory Review Committee is hereby abolished one year after the grants under this article have been made by the director.

(Added by Stats. 1995, Ch. 415, Sec. 8. Effective January 1, 1996.)

125240. Pursuant to the rules or criteria as the director may deem necessary, the Scientific Advisory Review Committee shall review and recommend approval of grant applications and monitor programs receiving grants under this article.

(Added by Stats. 1995, Ch. 415, Sec. 8. Effective January 1, 1996.)

125245. The director may make grants as follows:

(a) Individual research grants to scientists and facilities residing in this state that have research experience with basic and clinical investigations on Huntington’s disease and related disorders. Individual research grants shall not exceed twenty thousand dollars ($20,000).

(b) Interdisciplinary workshop grants to scientists and facilities for the purposes of facilitating interchange among an interdisciplinary group of investigators regarding problems in the treatment and care of patients as well as basic research, all of which may be applicable to a variety of genetic or neuro-degenerative disorders in addition to Huntington’s disease. Individual workshop grants shall not exceed twelve thousand five hundred dollars ($12,500).

(Added by Stats. 1995, Ch. 415, Sec. 8. Effective January 1, 1996.)

125250. Not more than 10 percent of any money appropriated for purposes of this article shall be utilized for the administration of this article.

(Added by Stats. 1995, Ch. 415, Sec. 8. Effective January 1, 1996.)