

By Mr. Chiocca of Bridgewater, petition of Allan R. Chiocca for the establishment within the Department of Public Health of an advisory committee to investigate and study inherited neurological degenerative diseases. Health Care.

The Commonwealth of Massachusetts

In the Year One Thousand Nine Hundred and Eighty-One.

AN ACT PROVIDING FOR AN INVESTIGATION AND STUDY OF HEREDOFAMILIAL NEURONAL DEGENERATIONS.

Be it enacted by the Senate and House of Representatives in General Court assembled, and by the authority of the same, as follows:

1 Chapter III of the General Laws is hereby amended by adding
2 after Section 6C the following new section:—

3 *Section 6D.* There shall be established within the department
4 an advisory committee for genetically handicapped persons, here-
5 inafter referred to as the committee. The committee shall be com-
6 posed of six members, one of whom shall be a geneticist, two of
7 whom shall be medical specialists, at least one of whom shall be a
8 neurologist involved in the medical treatment of individuals afflict-
9 ed with inherited neurological degenerative diseases in persons of
10 Portuguese ancestry, and three of whom shall be members of the
11 general public. The members of the committee shall serve without
12 compensation except for travel expenses for which they may re-
13 ceive reimbursement.

14 The department with the advice and recommendations of the
15 committee shall make an investigation and study into heredo-
16 familial neuronal degenerative diseases including, but not limited
17 to autosomal dominant motor system diseases in persons of Portu-
18 guese ancestry variously known as Machado's Disease, Joseph's
19 Disease, Azorean Disease, Machado-Joseph's Disease or spino-
20 nigro-dentatal degeneration, and also including Huntington's
21 Chorea and Freidreich's Ataxia and similar disorders. Such an in-
22 vestigation and study shall be conducted for the purposes of estab-

23 lishing and administering a program for the medical care, treat-
24 ment and counseling of genetically handicapped persons afflicted
25 with the aforementioned diseases.

26 The department, after receiving final recommendations from the
27 committee, is authorized to adopt such rules and regulations as are
28 deemed necessary for the establishment of a medical program for
29 those afflicted with Machado's Disease, Joseph's Disease, Azorean
30 Disease, Machado's-Joseph's Disease, spino-nigro-dentatal de-
31 generation, Huntington's Chorea and Friedreich's Ataxia and all
32 other heredo-familial neuronal degenerations to provide access to
33 educational, social, and medical support services, including but
34 not limited to transportation, emergency financial assistance,
35 home nursing care, family and genetic counseling to those at risk or
36 to those afflicted, financial assistance to those attending clinics and
37 related medical expenses such as prescription drugs, wheelchairs
38 and communication devices which serve to aid those afflicted.