S T A T E O F N E W Y O R K

3549

2009-2010 Regular Sessions

I N S E N A T E

March 24, 2009

Introduced by Sen. DUANE -- read twice and ordered printed, and when printed to be committed to the Committee on Health

AN ACT to amend the public health law, in relation to the control of progressive neurological diseases

THE PEOPLE OF THE STATE OF NEW YORK, REPRESENTED IN SENATE AND ASSEMBLY, DO ENACT AS FOLLOWS:

Section 1. The public health law is amended by adding a new article 20-B to read as follows:

ARTICLE 20-B

REPORTING OF PROGRESSIVE NEUROLOGICAL DISEASES

SECTION 2010. AMYOTROPHIC LATERAL SCLEROSIS; POWERS AND DUTIES OF COMMISSIONER.
2011. AMYOTROPHIC LATERAL SCLEROSIS; REGISTRY PURPOSE.
2012. REPORTING.
2013. AMYOTROPHIC LATERAL SCLEROSIS; REPORTS CONFIDENTIAL.
2014. AMYOTROPHIC LATERAL SCLEROSIS; COMPULSORY SUBMISSION FOR SUPERVISION OR INSPECTION NOT REQUIRED.

S 2010. AMYOTROPHIC LATERAL SCLEROSIS; POWERS AND DUTIES OF COMMISSIONER. THE COMMISSIONER SHALL, TO THE EXTENT THAT FUNDS ARE MADE AVAILABLE:

1. DEVELOP A SYSTEM TO COLLECT DATA ON AMYOTROPHIC LATERAL SCLEROSIS, INCLUDING INFORMATION RELEVANT TO INCIDENCE AND PREVALENCE OF THE DISEASE IN NEW YORK STATE, INCLUDING BUT NOT LIMITED TO MORTALITY, METHODS OF TREATMENT, PREVENTION AND CURE OF AMYOTROPHIC LATERAL SCLEROSIS, AND ALLIED DISEASES, NAMES AND LOCATIONS OF THE FACILITIES AVAILABLE IN THE SEVERAL COUNTIES AND CITIES OF THE STATE, FOR THE DIAGNOSIS AND TREATMENT OF THESE DISEASES, AND SHALL COOPERATE WITH LOCAL HEALTH AUTHORITIES, PHYSICIANS, HOSPITALS, CLINICS AND VOLUNTARY ASSOCIATIONS, IN THE DEVELOPMENT OF SUITABLE FACILITIES FOR THE DIAGNOSIS, TREATMENT AND CONTROL OF AMYOTROPHIC LATERAL SCLEROSIS.

EXPLANATION--Matter in ITALICS (underscored) is new; matter in brackets [ ] is old law to be omitted.

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2. ESTABLISH A STATEWIDE REGISTRY FOR THE COLLECTION AND STORAGE OF SUCH DATA TO INCLUDE A POPULATION-BASED REGISTRY OF CASES OF AMYOTROPHIC LATERAL SCLEROSIS IN NEW YORK STATE.

3. ESTABLISH A STATEWIDE IN-HOME BRAIN TO COMPUTER INTERFACE PILOT PROGRAM.

S 2011. AMYOTROPHIC LATERAL SCLEROSIS; REGISTRY PURPOSE. 1. PURPOSE. IT IS THE PURPOSE OF THE REGISTRY TO GATHER DATA CONCERNING

A. AMYOTROPHIC LATERAL SCLEROSIS, INCLUDING THE INCIDENCE AND PREVALENCE OF AMYOTROPHIC LATERAL SCLEROSIS IN NEW YORK STATE;

B. THE ENVIRONMENTAL AND OCCUPATIONAL FACTORS THAT MAY BE ASSOCIATED WITH THE DISEASE;

C. THE AGE, RACE OR ETHNICITY, GENDER, AND FAMILY HISTORY OF INDIVIDUALS WHO ARE DIAGNOSED WITH THE DISEASE.

2. BRAIN TO COMPUTER INTERFACE PILOT PROGRAM PURPOSE. THE GOAL OF THIS PILOT PROGRAM IS TO DEMONSTRATE THAT BRAIN TO COMPUTER INTERFACE TECHNOLOGY IS A CLINICALLY PRACTICAL AND IMPORTANT NEW COMMUNICATION AND CONTROL OPTION THAT CAN IMPROVE THE LIVES OF PEOPLE WITH AMYOTROPHIC LATERAL SCLEROSIS AND OTHER SEVERE MOTOR DISABILITIES.

3. REPORTING. WHENEVER AN EXAMINATION AND/OR TESTING DISCLOSES THE EXISTENCE OF AMYOTROPHIC LATERAL SCLEROSIS, THE PERSON MAKING SUCH EXAMINATION AND/OR TESTING OR THE DIAGNOSED PATIENT MAY REPORT IMMEDIATELY BUT NOT LATER THAN ONE HUNDRED EIGHTY DAYS THE SAME TOGETHER WITH ALL THE FACTS IN CONNECTION THEREWITH TO THE DEPARTMENT.

4. GUIDELINES. THE DEPARTMENT SHALL ESTABLISH AND UPDATE AS NECESSARY GUIDELINES DESIGNATING THE SPECIFIC DATA ELEMENTS TO BE REPORTED TO THE DEPARTMENT PURSUANT TO THIS SECTION. THE DEPARTMENT SHALL MAKE SUCH GUIDELINES AVAILABLE GENERALLY.

5. REGIONAL TRAINING. THE DEPARTMENT SHALL, TO THE EXTENT FUNDS ARE MADE AVAILABLE, ESTABLISH OR CONTRACT FOR REGIONAL TRAINING PROGRAMS TO PROVIDE TRAINING TO ANY AMYOTROPHIC LATERAL SCLEROSIS REPORTING FACILITY AND PHYSICIAN OR OTHER HEALTH CARE PROVIDER. SUCH REGIONAL TRAINING PROGRAMS SHALL PROVIDE TRAINING RELATING TO THE SPECIFIC DATA ELEMENTS WHICH MUST BE REPORTED PURSUANT TO THIS SECTION, THE DATA DICTIONARY ESTABLISHED PURSUANT TO THIS SECTION; TRAINING WILL ALSO BE PROVIDED RELATIVE TO THE OPERATION AND SUPPORT OF BRAIN TO COMPUTER INTERFACE TECHNOLOGY, AND IS INTENDED TO ENSURE QUALITY, TIMELY AND COMPLETE COMPLIANCE WITH THIS SECTION.

6. FAILURE TO COMPLY. WHERE AN AMYOTROPHIC LATERAL SCLEROSIS REPORTING FACILITY FAILS TO COMPLY WITH THE PROVISIONS OF THIS SECTION, THE DEPARTMENT MAY ELECT TO PERFORM REGISTRY SERVICES FOR SUCH FACILITY. SUCH AMYOTROPHIC LATERAL SCLEROSIS REPORTING FACILITY SHALL REIMBURSE THE DEPARTMENT FOR ACTUAL EXPENSES INCURRED.

7. FORM OF NOTICE. THE NOTICES REQUIRED BY THIS SECTION SHALL BE UPON FORMS SUPPLIED BY THE COMMISSIONER AND SHALL CONTAIN SUCH INFORMATION AS SHALL BE REQUIRED BY THE COMMISSIONER.

8. DEFINITION. FOR THE PURPOSE OF THIS SECTION, AN "AMYOTROPHIC LATERAL SCLEROSIS REPORTING FACILITY" MEANS A HOSPITAL AS DEFINED IN ARTICLE TWENTY-EIGHT OF THIS CHAPTER, CLINIC OR ANY ORGANIZATION CERTIFIED PURSUANT TO ARTICLE FORTY-FOUR OF THIS CHAPTER, OR OTHER SIMILAR PUBLIC OR PRIVATE INSTITUTION.

9. RULES AND REGULATIONS. THE COMMISSIONER SHALL HAVE THE POWER TO PROMULGATE ANY SUCH RULES AND REGULATIONS AS SHALL BE NECESSARY AND PROPER TO EFFECTUATE THE PURPOSES OF THIS SECTION.

S 2012. REPORTING. THE COMMISSIONER SHALL, SUBMIT AN ANNUAL REPORT TO THE GOVERNOR, THE TEMPORARY PRESIDENT OF THE SENATE AND THE SPEAKER OF THE ASSEMBLY. THE REPORT SHALL INCLUDE AN EVALUATION OF THE AMYOTROPHIC

LATERAL SCLEROSIS REGISTRY AS IT RELATES TO TIMELINESS, QUALITY AND COMPLETENESS; AN EVALUATION OF THE UTILITY OF THE REGISTRY FOR SCIENTIFIC RESEARCH; AN EVALUATION OF THE ACCESS, TIMELINESS AND QUALITY OF REPORTING INFORMATION TO RESEARCHERS AND OTHER SIMILAR INDIVIDUALS; AN EVALUATION OF THE REGISTRY'S DATA ELEMENTS, INCLUDING TREATMENT, STAGE OF DISEASE, OCCUPATION AND RESIDENCE; AN EVALUATION OF THE FEASIBILITY AND UTILITY OF INCLUSION OF OCCUPATIONAL HISTORY AND RESIDENCE HISTORY; AND AN EVALUATION OF INTEGRATING THE REGISTRY WITH OTHER DATA BASES MAINTAINED BY STATE AGENCIES AND DEPARTMENTS, INCLUDING THE STATEWIDE PLANNING AND RESEARCH COOPERATIVE SYSTEM.

S 2013. AMYOTROPHIC LATERAL SCLEROSIS; REPORTS CONFIDENTIAL. THE REPORTS OF AMYOTROPHIC LATERAL SCLEROSIS CASES MADE PURSUANT TO THE PROVISIONS OF THIS ARTICLE SHALL NOT BE DIVULGED OR MADE PUBLIC SO AS TO DISCLOSE THE IDENTITY OF ANY PERSON TO WHOM THEY RELATE, BY ANY PERSON, EXCEPT INSOFAR AS MAY BE AUTHORIZED IN THE SANITARY CODE.

S 2014. AMYOTROPHIC LATERAL SCLEROSIS; COMPULSORY SUBMISSION FOR SUPERVISION OR INSPECTION NOT REQUIRED. NOTHING IN THIS ARTICLE SHALL BE CONSTRUED TO COMPEL ANY INDIVIDUAL TO SUBMIT TO MEDICAL OR HEALTH DEPARTMENT SUPERVISION OR INSPECTION.

S 2. This act shall take effect immediately.