

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:

1 Section 1. The public health law is amended by adding a new article
2 20-B to read as follows:

3 A R T I C L E 20-B

4 R E P O R T I N G O F P R O G R E S S I V E N E U R O L O G I C A L D I S E A S E S

5 SECTION 2010. AMYOTROPHIC LATERAL SCLEROSIS; POWERS AND DUTIES OF
6 COMMISSIONER.

7 2011. AMYOTROPHIC LATERAL SCLEROSIS; REGISTRY PURPOSE.

8 2012. REPORTING.

9 2013. AMYOTROPHIC LATERAL SCLEROSIS; REPORTS CONFIDENTIAL.

10 2014. AMYOTROPHIC LATERAL SCLEROSIS; COMPULSORY SUBMISSION FOR
11 SUPERVISION OR INSPECTION NOT REQUIRED.

12 S 2010. AMYOTROPHIC LATERAL SCLEROSIS; POWERS AND DUTIES OF COMMIS-
13 SIONER. THE COMMISSIONER SHALL, TO THE EXTENT THAT FUNDS ARE MADE
14 AVAILABLE:

15 1. DEVELOP A SYSTEM TO COLLECT DATA ON AMYOTROPHIC LATERAL SCLEROSIS,
16 INCLUDING INFORMATION RELEVANT TO INCIDENCE AND PREVALENCE OF THE
17 DISEASE IN NEW YORK STATE, INCLUDING BUT NOT LIMITED TO MORTALITY, METH-
18 ODS OF TREATMENT, PREVENTION AND CURE OF AMYOTROPHIC LATERAL SCLEROSIS,
19 AND ALLIED DISEASES, NAMES AND LOCATIONS OF THE FACILITIES AVAILABLE IN
20 THE SEVERAL COUNTIES AND CITIES OF THE STATE, FOR THE DIAGNOSIS AND
21 TREATMENT OF THESE DISEASES, AND SHALL COOPERATE WITH LOCAL HEALTH
22 AUTHORITIES, PHYSICIANS, HOSPITALS, CLINICS AND VOLUNTARY ASSOCIATIONS,
23 IN THE DEVELOPMENT OF SUITABLE FACILITIES FOR THE DIAGNOSIS, TREATMENT
24 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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1 2. ESTABLISH A STATEWIDE REGISTRY FOR THE COLLECTION AND STORAGE OF
2 SUCH DATA TO INCLUDE A POPULATION-BASED REGISTRY OF CASES OF AMYOTROPHIC
3 LATERAL SCLEROSIS IN NEW YORK STATE.

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

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

8 A. AMYOTROPHIC LATERAL SCLEROSIS, INCLUDING THE INCIDENCE AND PREVA-
9 LENCE OF AMYOTROPHIC LATERAL SCLEROSIS IN NEW YORK STATE;

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

12 C. THE AGE, RACE OR ETHNICITY, GENDER, AND FAMILY HISTORY OF INDIVID-
13 UALS WHO ARE DIAGNOSED WITH THE DISEASE.

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

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

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

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

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

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

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

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

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

1 LATERAL SCLEROSIS REGISTRY AS IT RELATES TO TIMELINESS, QUALITY AND
2 COMPLETENESS; AN EVALUATION OF THE UTILITY OF THE REGISTRY FOR SCIENTIF-
3 IC RESEARCH; AN EVALUATION OF THE ACCESS, TIMELINESS AND QUALITY OF
4 REPORTING INFORMATION TO RESEARCHERS AND OTHER SIMILAR INDIVIDUALS; AN
5 EVALUATION OF THE REGISTRY'S DATA ELEMENTS, INCLUDING TREATMENT, STAGE
6 OF DISEASE, OCCUPATION AND RESIDENCE; AN EVALUATION OF THE FEASIBILITY
7 AND UTILITY OF INCLUSION OF OCCUPATIONAL HISTORY AND RESIDENCE HISTORY;
8 AND AN EVALUATION OF INTEGRATING THE REGISTRY WITH OTHER DATA BASES
9 MAINTAINED BY STATE AGENCIES AND DEPARTMENTS, INCLUDING THE STATEWIDE
10 PLANNING AND RESEARCH COOPERATIVE SYSTEM.

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

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

20 S 2. This act shall take effect immediately.