

5388

2009-2010 Regular Sessions

I N   A S S E M B L Y

February 13, 2009

---

Introduced by M. of A. MAISEL, DINOWITZ, BROOK-KRASNY, PHEFFER, JAFFEE  
-- Multi-Sponsored by -- M. of A. ESPAILLAT, V. LOPEZ, MARKEY, MAYER-  
SOHN, McENENY, REILLY, SWEENEY, WEISENBERG -- read once and referred  
to the Committee on Health

AN ACT to amend the public health law, in relation to creating a lymph-  
hedema and lymphatic diseases registry and creating a lymphedema and  
lymphatic diseases advisory board

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

1     Section 1. The public health law is amended by adding a new article 18  
2     to read as follows:

3                                     ARTICLE 18

4                     LYMPHEDEMA AND LYMPHATIC DISEASES REGISTRY;  
5                                     ADVISORY BOARD

6     SECTION 1800. DUTY TO REPORT.

7             1801. DEFINITIONS.

8             1802. CONTENTS OF REPORT; REGISTRY.

9             1803. DUTIES OF DEPARTMENT.

10            1804. DUTIES OF COMMISSIONER.

11            1805. LYMPHEDEMA AND LYMPHATIC DISEASES ADVISORY BOARD.

12     S 1800. DUTY TO REPORT. EVERY PHYSICIAN OR HEALTH CARE PROVIDER SHALL  
13     REPORT THE EXISTENCE OF LYMPHEDEMA AND LYMPHATIC DISEASE TO THE DEPART-  
14     MENT FOR COMPILATION INTO A REGISTRY OF INFORMATION AND DATA.

15     S 1801. DEFINITIONS. AS USED IN THIS ARTICLE:

16     1. "LYMPHEDEMA" SHALL MEAN AN ACCUMULATION OF LYMPHATIC FLUID IN THE  
17     INTERSTITIAL TISSUE THAT CAUSES SWELLING, MOST OFTEN IN THE ARMS AND/OR  
18     LEGS, AND OCCASIONALLY IN OTHER PARTS OF THE BODY, BY ANY CAUSE.

19     2. LYMPHATIC DISEASES SHALL INCLUDE, BUT NOT BE LIMITED TO: INSUFFI-  
20     CIENCY OF LYMPHATIC CIRCULATORY FUNCTION (TO INCLUDE ALL FORMS OF LYMP-  
21     HEDEMA), LIPEDEMA, COMPLEX CONGENITAL DISEASES OF THE LYMPHATIC VASCULA-  
22     TURE, INCLUDING LYMPHANGIOMATOSIS, LYMPHANGIOLEIO-MYOMATOSIS,

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

LBD07194-02-9

1 LYMPHANGIECTASIAS, LYMPHANGIOMAS, CYSTIC HYGROMAS, GORHAM'S DISEASE,  
2 LYMPHANGIOSARCOMA, AND COMPLEX VASCULAR/LYMPHATIC MALFORMATIONS.

3 S 1802. CONTENTS OF REPORT; REGISTRY. THE REPORT AS SET FORTH IN  
4 SECTION EIGHTEEN HUNDRED OF THIS ARTICLE SHALL BE DESIGNATED AS THE  
5 LYMPHEDEMA AND LYMPHATIC DISEASES REPORT AND SHALL CONTAIN INFORMATION  
6 WHICH THE COMMISSIONER, IN CONSULTATION WITH THE LYMPHEDEMA AND LYMPHATIC  
7 DISEASES ADVISORY BOARD ESTABLISHED IN SECTION EIGHTEEN HUNDRED FIVE  
8 OF THIS ARTICLE, DEEMS NECESSARY TO IDENTIFY PRIMARY, OR SOURCE CASES OF  
9 LYMPHEDEMA AND LYMPHATIC DISEASES AND SECONDARY CASES OF SUCH DISEASES,  
10 INVESTIGATE THE INCIDENCES AND PREVALENCE OF LYMPHEDEMA AND LYMPHATIC  
11 DISEASES, AND OTHER RELEVANT DATA AND FINDINGS WITH RESPECT THERETO.

12 S 1803. DUTIES OF DEPARTMENT. 1. THE LYMPHEDEMA AND LYMPHATIC DISEASES  
13 REPORTS PROVIDED BY PHYSICIANS AND HEALTH CARE PROVIDERS SHALL BE MAIN-  
14 TAINED BY THE DEPARTMENT IN A REGISTRY SUITABLE FOR RESEARCH PURPOSES,  
15 AND SHALL BE MADE AVAILABLE TO PERSONS AS SET FORTH IN SUBDIVISION TWO  
16 OF THIS SECTION.

17 2. NOTWITHSTANDING ANY INCONSISTENT PROVISION OF LAW, ALL INFORMATION  
18 COLLECTED PURSUANT TO THIS ARTICLE SHALL BE CONFIDENTIAL WITH RESPECT TO  
19 THE IDENTITY OF THE INDIVIDUAL PATIENT AND SHALL BE USED SOLELY FOR THE  
20 PURPOSES PROVIDED IN THIS ARTICLE. ACCESS TO SUCH INFORMATION SHALL BE  
21 LIMITED TO AUTHORIZED EMPLOYEES OF THE DEPARTMENT AND PERSONS WITH A  
22 VALID SCIENTIFIC INTEREST AND QUALIFICATIONS, AS DEFINED BY THE COMMIS-  
23 SIONER, WHO ARE ENGAGED IN DEMOGRAPHIC, EPIDEMIOLOGICAL OR OTHER SIMILAR  
24 STUDIES RELATED TO HEALTH, AND WHO AGREE, IN WRITING, TO MAINTAIN CONFIDEN-  
25 TIALITY AS ESTABLISHED BY THE COMMISSIONER AND IN ACCORDANCE WITH  
26 APPLICABLE LOCAL, STATE AND FEDERAL LAWS AND REGULATIONS.

27 3. THE DEPARTMENT SHALL MAINTAIN AN ACCURATE RECORD OF ALL PERSONS WHO  
28 ARE GIVEN ACCESS TO THE INFORMATION CONTAINED IN THE LYMPHEDEMA AND  
29 LYMPHATIC DISEASES REGISTRY. THE RECORD SHALL INCLUDE THE NAME OF THE  
30 PERSON AUTHORIZING ACCESS, THE NAME, TITLE AND ORGANIZATIONAL AFFIL-  
31 IATION OF THE PERSON GIVEN ACCESS, DATES OF ACCESS, AND THE SPECIFIC  
32 PURPOSE FOR WHICH INFORMATION IS TO BE USED. THE RECORD OF ACCESS SHALL  
33 BE OPEN TO PUBLIC INSPECTION DURING NORMAL OPERATING HOURS OF THE  
34 DEPARTMENT.

35 4. ANY PERSON WHO, IN VIOLATION OF A WRITTEN AGREEMENT TO MAINTAIN  
36 CONFIDENTIALITY, DISCLOSES ANY INFORMATION PROVIDED PURSUANT TO THIS  
37 SECTION, OR WHO USES INFORMATION PROVIDED PURSUANT TO THIS SECTION IN A  
38 MANNER OTHER THAN THAT PRESCRIBED BY THE COMMISSIONER, MAY BE DENIED  
39 FURTHER ACCESS TO ANY CONFIDENTIAL INFORMATION MAINTAINED BY THE DEPART-  
40 MENT AND MAY BE SUBJECT TO PENALTY OF A FINE AS DETERMINED BY THE  
41 COMMISSIONER.

42 S 1804. DUTIES OF COMMISSIONER. THE COMMISSIONER SHALL PROMULGATE  
43 RULES AND REGULATIONS TO IMPLEMENT THE PROVISIONS OF THIS ARTICLE,  
44 INCLUDING BUT NOT LIMITED TO:

45 1. ESTABLISHING THE FORM, CONTENT AND MANNER OF REPORTING BY PHYSI-  
46 CIANS AND HEALTH CARE PROVIDERS FOR FILING THE LYMPHEDEMA AND/OR LYMPH-  
47 HATIC DISEASES INFORMATION DATA;

48 2. DEVELOPING AND MAINTAINING THE LYMPHEDEMA AND LYMPHATIC DISEASES  
49 REGISTRY;

50 3. DEVELOPING GUIDELINES FOR THE PERMISSIBLE USES FOR THE INFORMATION  
51 MADE AVAILABLE PURSUANT TO THIS ARTICLE;

52 4. ESTABLISHING PROCEDURES TO MAINTAIN THE CONFIDENTIALITY OF INFORMA-  
53 TION PROVIDED TO PERSONS PURSUANT TO THIS ARTICLE;

54 5. ESTABLISHING PENALTIES FOR WILLFUL VIOLATIONS OF WRITTEN AGREE-  
55 MENTS TO MAINTAIN CONFIDENTIALITY; AND

6. ESTABLISHING THE NECESSARY PROCEDURES TO MEET AND SUPPORT THE GOALS OF A NATIONAL LYMPHEDEMA AND LYMPHATIC DISEASES REGISTRY ESTABLISHED BY THE FEDERAL GOVERNMENT OR A NATIONALLY RECOGNIZED CENTRAL LYMPHATIC DISEASE ORGANIZATION.

S 1805. LYMPHEDEMA AND LYMPHATIC DISEASES ADVISORY BOARD. 1. THERE IS HEREBY ESTABLISHED IN THE DEPARTMENT THE LYMPHEDEMA AND LYMPHATIC DISEASES ADVISORY BOARD TO BE COMPOSED OF NINE MEMBERS WHO SHALL BE RESIDENTS OF THE STATE AND SHALL BE APPOINTED IN THE FOLLOWING MANNER: TWO SHALL BE APPOINTED BY THE TEMPORARY PRESIDENT OF THE SENATE; TWO SHALL BE APPOINTED BY THE SPEAKER OF THE ASSEMBLY; AND FIVE SHALL BE APPOINTED BY THE GOVERNOR. THE GOVERNOR SHALL DESIGNATE THE CHAIR OF THE ADVISORY BOARD. THE MAJORITY OF THE MEMBERS OF THE BOARD SHALL BE REPRESENTATIVES AND EXPERTS IN THE AREA OF LYMPHATIC RESEARCH, BIOTECHNOLOGY RESEARCH, TREATMENT OF LYMPHEDEMA AND/OR LYMPHATIC DISEASES. AT LEAST ONE APPOINTEE SHALL BE AN INDIVIDUAL OR AN INDIVIDUAL WITH A CLOSE FAMILY MEMBER DIAGNOSED WITH EITHER PRIMARY OR SECONDARY LYMPHEDEMA OR A LYMPHATIC DISEASE. AT LEAST ONE APPOINTEE SHALL REPRESENT AN ORGANIZATION DEDICATED SOLELY TO LYMPHEDEMA AND LYMPHATIC DISEASE EDUCATION, AWARENESS AND RESEARCH. THE MEMBERS OF SUCH BOARD SHALL SERVE FOR A TERM OF TWO YEARS. VACANCIES SHALL BE FILLED IN THE SAME MANNER AS THE ORIGINAL APPOINTMENTS. THE ADVISORY BOARD SHALL MEET AT LEAST THREE TIMES A YEAR, AT THE REQUEST OF THE CHAIR. THE MEMBERS OF THE BOARD SHALL RECEIVE NO COMPENSATION FOR THEIR SERVICES, BUT SHALL BE ALLOWED THEIR ACTUAL AND NECESSARY EXPENSES INCURRED IN PERFORMANCE OF THEIR DUTIES.

2. THE ADVISORY BOARD SHALL BE RESPONSIBLE FOR ADVISING THE COMMISSIONER WITH RESPECT TO THE IMPLEMENTATION OF THIS ARTICLE, INCLUDING BUT NOT LIMITED TO THE FOLLOWING:

(A) THE DEVELOPMENT AND MAINTENANCE OF THE LYMPHEDEMA AND LYMPHATIC DISEASES REGISTRY;

(B) THE TYPE OF INFORMATION TO BE COLLECTED AND STORED IN THE REGISTRY;

(C) THE MANNER IN WHICH SUCH DATA IS TO BE COLLECTED;

(D) THE USE AND AVAILABILITY OF SUCH DATA INCLUDING GUIDELINES FOR SUCH USE; AND

(E) THE NECESSARY PROCEDURES TO MEET AND SUPPORT THE GOALS OF A NATIONAL LYMPHEDEMA AND LYMPHATIC DISEASES REGISTRY ESTABLISHED BY THE FEDERAL GOVERNMENT OR A NATIONALLY RECOGNIZED CENTRAL LYMPHATIC DISEASE ORGANIZATION, IF SUCH REGISTRY IS CREATED PRIOR TO OR AFTER THE EFFECTIVE DATE OF THIS ARTICLE.

3. THE ADVISORY BOARD, IN COLLABORATION WITH THE DEPARTMENT, SHALL PROVIDE GUIDANCE TO THE DEPARTMENT WITH RESPECT TO PROVIDING EDUCATION AND PUBLIC AWARENESS ON LYMPHEDEMA AND LYMPHATIC DISEASES, INCLUDING BUT NOT LIMITED TO:

(A) RAISING PUBLIC AWARENESS ON THE CAUSES AND NATURE OF PRIMARY AND SECONDARY LYMPHEDEMA AND LYMPHATIC DISEASES; PREVENTION; EARLY DIAGNOSIS; CURRENT AND NEW AND EMERGING OPTIONS FOR TREATMENT AND THERAPY; RESEARCH; MEDICAL INSURANCE; AND LONG-TERM CHRONIC CARE ISSUES.

(B) IDENTIFYING AND EXAMINING THE LIMITATIONS OF EXISTING LAWS, REGULATIONS, PROGRAMS, AND SERVICES WITH REGARD TO LYMPHEDEMA AND LYMPHATIC DISEASES. SUCH INFORMATION SHALL BE REPORTED, WITH RECOMMENDATIONS, TO THE GOVERNOR, THE TEMPORARY PRESIDENT OF THE SENATE AND THE SPEAKER OF THE ASSEMBLY.

(C) FACILITATING COORDINATION OF AND COMMUNICATION AMONG STATE AND LOCAL AGENCIES AND ORGANIZATIONS REGARDING FACILITATING TREATMENTS,

1 THERAPY, AND NEW AND EMERGING RESEARCH FOR LYMPHEDEMA AND LYMPHATIC  
2 DISEASES.

3 (D) RECEIVING AND CONSIDERING REPORTS AND TESTIMONY FROM INDIVIDUALS,  
4 LOCAL HEALTH DEPARTMENTS, COMMUNITY-BASED ORGANIZATIONS, VOLUNTARY  
5 HEALTH ORGANIZATIONS, AND OTHER PUBLIC AND PRIVATE ORGANIZATIONS STATE-  
6 WIDE TO LEARN ABOUT LYMPHEDEMA AND LYMPHATIC DISEASES PREVENTION, DIAG-  
7 NOSIS, TREATMENT, THERAPY AND NEW AND EMERGING RESEARCH.

8 (E) PROVIDING RESOURCES AND INFORMATION TO PATIENTS AND HEALTH CARE  
9 PROVIDERS ABOUT LYMPHEDEMA AND LYMPHATIC DISEASES PREVENTION, DIAGNOSIS,  
10 TREATMENT, THERAPY AND NEW AND EMERGING RESEARCH IN ORDER TO IMPROVE THE  
11 QUALITY OF LIFE FOR THOSE DIAGNOSED AND RECEIVING TREATMENT AND/OR THER-  
12 APY FOR LYMPHEDEMA AND LYMPHATIC DISEASES IN NEW YORK.

13 4. THE ADVISORY BOARD SHALL ISSUE A REPORT ON AN ANNUAL BASIS INDICAT-  
14 ING THE YEAR'S ACTIVITIES, GOALS AND OBJECTIVES, ACHIEVEMENTS, AND PLANS  
15 FOR THE FOLLOWING YEAR. THE ANNUAL REPORT SHALL ALSO INCLUDE SHORT AND  
16 LONG TERM STRATEGIC GOALS AND OPERATIONAL OBJECTIVES FOR ADDRESSING  
17 LYMPHEDEMA AND LYMPHATIC DISEASE HEALTHCARE AND RESEARCH.

18 S 2. This act shall take effect immediately.