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

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2009-2010 Regular Sessions

I N A S S E M B L Y

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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 lymphedema 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 ASSEMBLY, DO ENACT AS FOLLOWS:

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

ARTICLE 18

LYMPHEDEMA AND LYMPHATIC DISEASES REGISTRY; ADVISORY BOARD

SECTION 1800. DUTY TO REPORT.
1801. DEFINITIONS.
1802. CONTENTS OF REPORT; REGISTRY.
1803. DUTIES OF DEPARTMENT.
1804. DUTIES OF COMMISSIONER.
1805. LYMPHEDEMA AND LYMPHATIC DISEASES ADVISORY BOARD.

S 1800. DUTY TO REPORT. EVERY PHYSICIAN OR HEALTH CARE PROVIDER SHALL REPORT THE EXISTENCE OF LYMPHEDEMA AND LYMPHATIC DISEASE TO THE DEPARTMENT FOR COMPILATION INTO A REGISTRY OF INFORMATION AND DATA.

S 1801. DEFINITIONS. AS USED IN THIS ARTICLE:

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

2. LYMPHATIC DISEASES SHALL INCLUDE, BUT NOT BE LIMITED TO: INSUFFICIENCY OF LYMPHATIC CIRCULATORY FUNCTION (TO INCLUDE ALL FORMS OF LYMPHEDEMA), LIPEDEMA, COMPLEX CONGENITAL DISEASES OF THE LYMPHATIC VASCULATURE, INCLUDING LYMPHANGIOMATOSIS, LYMPHANGIOLEIO-MYOMATOSIS,

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

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

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

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

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

3. THE DEPARTMENT SHALL MAINTAIN AN ACCURATE RECORD OF ALL PERSONS WHO ARE GIVEN ACCESS TO THE INFORMATION CONTAINED IN THE LYMPHEDEMA AND LYMPHATIC DISEASES REGISTRY. THE RECORD SHALL INCLUDE THE NAME OF THE PERSON AUTHORIZING ACCESS, THE NAME, TITLE AND ORGANIZATIONAL AFFILIATION OF THE PERSON GIVEN ACCESS, DATES OF ACCESS, AND THE SPECIFIC PURPOSE FOR WHICH INFORMATION IS TO BE USED. THE RECORD OF ACCESS SHALL BE OPEN TO PUBLIC INSPECTION DURING NORMAL OPERATING HOURS OF THE DEPARTMENT.

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

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

1. ESTABLISHING THE FORM, CONTENT AND MANNER OF REPORTING BY PHYSICIANS AND HEALTH CARE PROVIDERS FOR FILING THE LYMPHEDEMA AND/OR LYMPHATIC DISEASES INFORMATION DATA;

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

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

4. ESTABLISHING PROCEDURES TO MAINTAIN THE CONFIDENTIALITY OF INFORMATION PROVIDED TO PERSONS PURSUANT TO THIS ARTICLE;

5. ESTABLISHING PENALTIES FOR WILLFUL VIOLATIONS OF WRITTEN AGREEMENTS 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,

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

(D) RECEIVING AND CONSIDERING REPORTS AND TESTIMONY FROM INDIVIDUALS, LOCAL HEALTH DEPARTMENTS, COMMUNITY-BASED ORGANIZATIONS, VOLUNTARY HEALTH ORGANIZATIONS, AND OTHER PUBLIC AND PRIVATE ORGANIZATIONS STATEWIDE TO LEARN ABOUT LYMPHEDEMA AND LYMPHATIC DISEASES PREVENTION, DIAGNOSIS, TREATMENT, THERAPY AND NEW AND EMERGING RESEARCH.

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

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

S 2. This act shall take effect immediately.