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

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I N A S S E M B L Y

January 16, 2014

Introduced by M. of A. ROSENTHAL, BROOK-KRASNY, LAVINE, PERRY, ROBINSON, ROBERTS, McKEVITT, BORELLI -- Multi-Sponsored by -- M. of A. BRENNAN, COOK, CROUCH, MARKEY, SWEENEY, TITONE, WEINSTEIN -- read once and referred to the Committee on Health

AN ACT to amend the public authorities law, in relation to establishing a lymphedema and lymphatic diseases research grants program; and to amend the state finance law, in relation to creating the lymphedema and lymphatic diseases research and education fund

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

Section 1. The public authorities law is amended by adding a new section 3153-a to read as follows:

S 3153-A. LYMPHEDEMA AND LYMPHATIC DISEASES RESEARCH GRANTS PROGRAM. 1. THE FOUNDATION SHALL, WITHIN AVAILABLE APPROPRIATIONS, ESTABLISH THE LYMPHEDEMA AND LYMPHATIC DISEASES RESEARCH GRANTS PROGRAM, HEREAFTER "GRANTS PROGRAM." THE GRANTS PROGRAM SHALL BE ADMINISTERED BY THE FOUNDATION, IN CONSULTATION WITH THE DEPARTMENT OF HEALTH. SUCH GRANTS PROGRAM FUNDS SHALL BE USED TO PROVIDE FINANCIAL ASSISTANCE IN THE FORM OF GRANTS, NOT TO EXCEED FIFTY THOUSAND DOLLARS PER GRANT, TO NEW YORK STATE BIOMEDICAL RESEARCH INSTITUTIONS FOR WORKING CAPITAL TO FURTHER NEW AND EMERGING RESEARCH AND DEVELOPMENT FOR THE DIAGNOSIS AND TREATMENT OF LYMPHEDEMA AND LYMPHATIC DISEASES. SUCH GRANTS SHALL BE AWARDED ON A COMPETITIVE BASIS TO BIOMEDICAL RESEARCH INSTITUTIONS RESPONDING TO REQUESTS FOR PROPOSALS ISSUED BY THE FOUNDATION WHEN FUNDS ARE APPROPRIATED.

2. (A) "BIOMEDICAL RESEARCH INSTITUTION" SHALL MEAN A NOT-FOR-PROFIT UNIVERSITY, COLLEGE, HOSPITAL, PRIVATE OR FEDERAL RESEARCH LABORATORY LOCATED IN NEW YORK STATE, OR A CONSORTIUM OF SUCH ENTITIES, THAT CONDUCTS AN INTENSIVE AND ONGOING PROGRAM OF RESEARCH AND DEVELOPMENT DIRECTLY RELATED TO LYMPHEDEMA AND/OR LYMPHATIC DISEASES RESEARCH.

(B) "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, FROM ANY CAUSE.

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

LBD13015-01-3

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

3. IN ADDITION TO SUCH OTHER CRITERIA AS THE FOUNDATION MAY ADOPT IN RULES AND REGULATIONS FOR THE CONSIDERATION OF APPLICATIONS FOR GRANTS PURSUANT TO SUBDIVISION ONE OF THIS SECTION, THE FOUNDATION SHALL:

(A) DETERMINE THAT THE APPLICANT IS UNABLE TO OBTAIN SUFFICIENT FUNDING ON REASONABLE TERMS FROM OTHER PUBLIC OR PRIVATE SOURCES TO PERMIT THE INSTITUTION'S PLANNED INVESTMENT TO PROCEED WITHOUT THE REQUIRED ASSISTANCE;

(B) GIVE PRIORITY TO THOSE APPLICATIONS FOR ASSISTANCE FROM BIOMEDICAL RESEARCH INSTITUTIONS THAT SECURE PRIVATE SUPPORT FOR RESEARCH OR COMMIT NEW RESOURCES TO THE EXPANSION OF LYMPHEDEMA AND LYMPHATIC DISEASES RESEARCH; AND

(C) CONSIDER THE POTENTIAL LONG TERM ECONOMIC BENEFITS TO THE STATE OF AWARDING THE SPECIFIC GRANT AND WHETHER THE GRANT WILL RESULT IN A REASONABLE LIKELIHOOD OF SUCCESS IN MEETING THE PURPOSES FOR WHICH IT WAS SOUGHT BY THE APPLICANT.

4. THE FOUNDATION, IN CONSULTATION WITH THE DEPARTMENT OF HEALTH, MAY APPLY TO THE NATIONAL INSTITUTES OF HEALTH, THE UNITED STATES DEPARTMENT OF HEALTH AND HUMAN SERVICES, AND OTHER APPROPRIATE FEDERAL, PUBLIC, AND PRIVATE ENTITIES FOR FUNDING. SUCH MONIES SHALL BE DEPOSITED INTO THE LYMPHEDEMA AND LYMPHATIC DISEASES RESEARCH AND EDUCATION FUND, ESTABLISHED PURSUANT TO SECTION NINETY-NINE-V OF THE STATE FINANCE LAW.

5. THE FOUNDATION SHALL SUBMIT TO THE GOVERNOR, THE SPEAKER OF THE ASSEMBLY, THE TEMPORARY PRESIDENT OF THE SENATE, AND TO ANY OTHER STATE LEGISLATOR AT HIS OR HER REQUEST, A REPORT ON THE GRANTS PROGRAM BY SEPTEMBER FIRST, TWO THOUSAND FIFTEEN AND ANNUALLY THEREAFTER. SUCH REPORT SHALL INCLUDE, FOR EACH GRANT AWARDED, THE NAME AND LOCATION OF THE RECIPIENT, A DESCRIPTION OF THE PRODUCT, DEVICE, TECHNIQUE, SYSTEM OR PROCESS BEING RESEARCHED AND DEVELOPED, THE RECIPIENT'S RELATIONSHIP TO THE RESEARCH INSTITUTION, THE AMOUNT AND USE OF THE GRANT, THE TOTAL PROJECT COST, AND SUCH OTHER INFORMATION AS THE FOUNDATION SHALL DEEM APPROPRIATE. SUCH REPORT SHALL ALSO INCLUDE A LIST OF ALL APPLICANTS AND THEIR CONTACT INFORMATION, REGARDLESS OF RECEIVING A GRANT, IN ORDER TO HELP DEMONSTRATE THE NEED FOR FUTURE FUNDS.

6. NOTHING IN THIS SECTION SHALL REQUIRE THE FOUNDATION TO DISCLOSE ANY MATTERS INVOLVING CONFIDENTIAL INTELLECTUAL PROPERTY OR WORK PRODUCT, WHETHER PATENTABLE OR NOT, INCLUDING ANY FORMULA, PLAN, PATTERN, PROCESS, TOOL, MECHANISM, COMPOUND, PROCEDURE, PRODUCTION DATA OR COMPILATION OF INFORMATION, WHICH IS NOT PATENTED, BUT WHICH IS KNOWN ONLY TO CERTAIN INDIVIDUALS WHO ARE USING IT TO FABRICATE, PRODUCE OR COMPOUND AN ARTICLE OF TRADE OR SERVICE HAVING COMMERCIAL VALUE AND WHICH GIVES ITS USER AN OPPORTUNITY TO OBTAIN A BUSINESS ADVANTAGE OVER COMPETITORS WHO DO NOT KNOW IT OR USE IT.

S 2. The state finance law is amended by adding a new section 99-v to read as follows:

S 99-V. LYMPHEDEMA AND LYMPHATIC DISEASES RESEARCH AND EDUCATION FUND. 1. THERE IS HEREBY ESTABLISHED IN THE JOINT CUSTODY OF THE COMMISSIONER OF TAXATION AND FINANCE AND THE COMPTROLLER, A SPECIAL FUND TO BE KNOWN AS THE LYMPHEDEMA AND LYMPHATIC DISEASES RESEARCH AND EDUCATION FUND, HEREAFTER THE "FUND".

2. SUCH FUND SHALL CONSIST OF ALL MONIES APPROPRIATED, CREDITED, OR TRANSFERRED THERETO FROM ANY OTHER FUND OR SOURCE PURSUANT TO LAW. NOTHING CONTAINED IN THIS SECTION SHALL PREVENT THE STATE FROM RECEIVING GRANTS, GIFTS OR BEQUESTS FOR THE PURPOSES OF THE FUND AS DEFINED IN THIS SECTION AND DEPOSITING THEM INTO THE FUND ACCORDING TO LAW.

3. MONIES OF THE FUND SHALL BE EXPENDED ONLY FOR LYMPHEDEMA AND LYMPHATIC DISEASES RESEARCH AND EDUCATION PROJECTS APPROVED BY THE DEPARTMENT OF HEALTH.

4. (A) "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, REGARDLESS OF CAUSE.

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

(C) "LYMPHEDEMA AND LYMPHATIC DISEASES RESEARCH AND EDUCATION PROJECTS" SHALL MEAN RESEARCH BY QUALIFIED RESEARCHERS, AS DETERMINED BY THE DEPARTMENT OF HEALTH, TO STIMULATE RESEARCH ON THE PATHOGENESIS AND NEW TREATMENTS FOR LYMPHEDEMA AND LYMPHATIC DISEASES. EDUCATION PROJECTS ARE THOSE PROJECTS WHICH PROMOTE AND PROVIDE INFORMATION ON LYMPHEDEMA AND LYMPHATIC DISEASES INCLUDING: PREVENTION, DIAGNOSIS, TREATMENT, LONG-TERM CHRONIC CARE, AND/OR RESEARCH BY QUALIFIED ORGANIZATIONS AS DETERMINED BY THE DEPARTMENT OF HEALTH.

5. MONIES SHALL BE PAYABLE FROM THE FUND ON THE AUDIT AND WARRANT OF THE COMPTROLLER ON VOUCHERS APPROVED AND CERTIFIED BY THE COMMISSIONER OF HEALTH.

6. TO THE EXTENT PRACTICABLE, THE COMMISSIONER OF HEALTH SHALL ENSURE THAT ALL MONIES RECEIVED DURING A FISCAL YEAR ARE EXPENDED PRIOR TO THE END OF THAT FISCAL YEAR.

S 3. This act shall take effect immediately.