

1249

2013-2014 Regular Sessions

I N   S E N A T E

(PREFILED)

January 9, 2013

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Introduced by Sens. PERKINS, HASSELL-THOMPSON, STAVISKY -- read twice  
and ordered printed, and when printed to be committed to the Committee  
on Health

AN ACT creating the New York Stem Cell Research Institute

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

1     Section 1. Short title. This act shall be known and may be cited as  
2     the "New York Stem Cell Research Institute act".

3     S 2. Legislative intent. Millions of children and adults suffer from  
4     devastating diseases or injuries that are currently incurable, including  
5     cancer, diabetes, heart disease, Parkinson's disease, spinal cord injuries,  
6     blindness, Lou Gehrig's disease, HIV/AIDS, mental health disorders,  
7     multiple sclerosis, Huntington's disease, and more than seventy  
8     other diseases and injuries.

9     Recently, medical science has discovered a new way to attack chronic  
10    diseases and injuries. The cure and treatment of these diseases can  
11    potentially be accomplished through the use of new regenerative medical  
12    therapies including a special type of human cells, called stem cells.  
13    These life-saving medical breakthroughs can only happen if adequate  
14    funding is made available to advance stem cell research, develop therapies,  
15    and conduct clinical trials.

16    Unfortunately, the federal government is not providing the adequate  
17    funding necessary for the urgent research and facilities needed to  
18    develop stem cell therapies to treat and cure diseases and serious injuries.  
19    This critical funding gap currently prevents the rapid advancement  
20    of research that could benefit millions of New Yorkers.

21    S 3. New York Stem Cell Research Institute. a. There is hereby created  
22    an institute to be known as the New York Stem Cell Research Institute,  
23    which shall have the following purposes:

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

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(1) To make grants and loans for stem cell research, for research facilities, and for other vital research opportunities to realize therapies, protocols, and/or medical procedures that will result in, as speedily as possible, the cure for, and/or substantial mitigation of, major diseases, injuries, and orphan diseases.

(2) To support all stages of the process of developing cures, from laboratory research through successful clinical trials.

(3) To establish appropriate regulatory standards and oversight bodies for research and facilities development.

b. No fund authorized for, or made available to, the institute shall be used for research involving human reproductive cloning.

c. Funds authorized for, or made available to, the institute shall be continuously appropriated without regard to fiscal year, be available and used only for the purposes provided in this act, and shall not be subject to appropriation or transfer by the legislature or the governor for any other purpose.

S 4. There shall be established within the institute the New York state stem cell board, hereinafter, the board, which shall govern the institute and is hereby vested with full power, authority, and jurisdiction over the institute.

S 5. The New York state stem cell board. a. The board shall be composed of nineteen members, who shall be appointed in the following manner: five shall be appointed by the governor; three shall be appointed by the temporary president of the senate; two by the minority leader of the senate; three shall be appointed by the speaker of the assembly; two by the minority leader of the assembly; two by the state comptroller; and two by the attorney general. The members of the board shall be representative of the public, not-for-profit academic and research institutions, life science commercial entities, and disease advocacy groups.

b. All appointments shall be made within forty days of the effective date of this act. In the event that any of the appointments are not completed within the permitted time frame, the board shall proceed to operate with the appointments that are in place, provided that at least sixty percent of the appointments have been made.

c. Board members shall serve six-year terms. Members shall serve a maximum of two terms. If a vacancy occurs within a term, the appointing authority shall serve a maximum of two terms. If a vacancy occurs within a term, the appointing authority shall appoint a replacement member within thirty days to serve the remainder of the term. When a term expires, the appointing authority shall appoint a member within thirty days. The board members shall continue to serve until their replacements are appointed.

S 6. The board shall have the following powers and duties: a. The board shall elect a chairperson and vice chairperson within forty days of the effective date of this act. Each constitutional officer shall nominate a candidate for chairperson and another candidate for vice chairperson. The chairperson and vice chairperson shall each be elected for a term of six years. The chairperson and vice chairperson of the board shall be full or part time employees of the institute and shall meet the following criteria:

(1) have a documented history in successful stem cell research advocacy;

(2) have experience with state and federal legislative processes that must include some experience with medical legislative approvals of standards and/or funding;

(3) are not concurrently employed by or on leave from any prospective grant or loan recipient institutions in New York;

(4) have experience with governmental agencies or institutions, either executive or board position;

(5) have experience with the process of establishing governmental standards and procedures;

(6) have legal experience with the legal review of proper governmental authority for the exercise of government agency or government institutional powers;

(7) have direct knowledge and experience in bond financing.

b. Actions of the board may be taken only by a majority vote of a quorum of the board.

c. The board shall oversee the operations of the institute.

d. The board shall develop annual and long-term strategic research and financial plans for the institute.

e. The board shall make final decisions on research standards and grant awards in New York.

f. Ensure the completion of an annual financial audit of the institute's operations.

g. Issue public reports on the activities of the institute.

h. Establish policies regarding intellectual property rights arising from research funded by the institute.

i. Establish rules and guidelines for the operation of the board and its working groups.

j. Perform all other acts necessary or appropriate in the exercise of its power, authority, and jurisdiction over the institute.

k. Adopt, amend, and rescind rules and regulations to carry out the purposes and provisions of this act, and to govern the procedures of the board. These rules and regulations shall be adopted in accordance with the state administrative procedure act.

S 7. Public and financial accountability standards. a. Annual public report. The institute shall issue an annual report to the public, which sets forth its activities, grants awarded, grants in progress, research accomplishments, and future program directions. Each annual report shall include, but not be limited to, the following:

(1) the number and dollar amounts of research and facilities grants;

(2) the grantees for the prior year;

(3) the institute's administrative expenses;

(4) an assessment of the availability of funding for stem cell research from sources other than the institute;

(5) a summary of research findings, including promising new research areas;

(6) an assessment of the relationship between the institute's grants and the overall strategy of its research program;

(7) a report of the institute's strategic research and financial plans.

b. Independent financial audit for review by state comptroller. The institute shall annually commission an independent financial audit of its activities from a certified public accounting firm, which shall be provided to the state comptroller, who shall review the audit and annually issue a public report of that review.

c. Citizen's financial accountability oversight committee. There shall be a citizen's financial accountability oversight committee chaired by the state comptroller. This committee shall review the annual financial audit, the state comptroller's report and evaluation of that audit, and the financial practices of the institute. The state comptroller, the

1 state treasurer, the temporary president of the senate, the speaker of  
2 the assembly, and the chairperson of the board shall each appoint a  
3 public member of the committee. Committee members shall have medical  
4 backgrounds and knowledge of relevant financial matters. The committee  
5 shall provide recommendations on the institute's financial practice and  
6 performance. The state comptroller shall provide staff support. The  
7 committee shall hold a public meeting, with appropriate notice, and with  
8 a formal public comment period. The committee shall evaluate public  
9 comments and include appropriate summaries in its annual report. The  
10 board shall provide funds for the per diem expenses of the committee  
11 members and for publication of the annual report.

12 S 8. Conflicts of interest. a. No member of the board shall make,  
13 participate in making, or in any way attempt to use his or her official  
14 position to influence a decision to approve or award a grant, loan, or  
15 contract to his or her employer, but a member may participate in a deci-  
16 sion to approve or award a grant, loan, or contract to a nonprofit enti-  
17 ty in the same field as his or her employer.

18 b. A member of the board may participate in a decision to approve or  
19 award a grant, loan, or contract to an entity for the purpose of  
20 research involving a disease from which a member or his or her immediate  
21 family suffers or in which the member has an interest as a represen-  
22 tative of a disease advocacy organization.

23 c. The adoption of standards is not a decision subject to this  
24 section.

25 d. Service as a member of the board by a member of the faculty or  
26 administration of any system of the state university shall not, by  
27 itself, be deemed to be inconsistent, incompatible, in conflict with, or  
28 inimical to the duties of the board member as a member of the faculty or  
29 administration of any system of the state university and shall not  
30 result in the automatic vacation of either such office.

31 e. Service as a member of the board by a representative or employee of  
32 a disease advocacy organization, a nonprofit academic and research  
33 institution, or a life science commercial entity shall not be deemed to  
34 be inconsistent, incompatible, in conflict with, or inimical to the  
35 duties of the board member as a representative or employee of that  
36 organization, institution, or entity.

37 S 9. Patent royalties and license revenues. The board shall establish  
38 standards that require that all grants and loan awards be subject to  
39 intellectual property agreements that balance the opportunity of the  
40 state of New York to benefit from the patents, royalties, and licenses  
41 that result from basic research, therapy development, and clinical  
42 trials with the need to assure that essential medical research is not  
43 unreasonably hindered by the intellectual property agreements.

44 S 10. Preference for New York suppliers. The board shall establish  
45 standards to ensure that grantees purchase goods and services from New  
46 York suppliers to the extent reasonably possible, in a good faith effort  
47 to achieve a goal of more than fifty percent of such purchases from New  
48 York suppliers.

49 S 11. This act shall take effect immediately.