

1249

2013-2014 Regular Sessions

I N S E N A T E

(PREFILED)

January 9, 2013

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 inju-  
6 ries, blindness, Lou Gehrig's disease, HIV/AIDS, mental health disor-  
7 ders, 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 thera-  
15 pies, 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 inju-  
19 ries. 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 (1) To make grants and loans for stem cell research, for research  
2 facilities, and for other vital research opportunities to realize thera-  
3 pies, protocols, and/or medical procedures that will result in, as  
4 speedily as possible, the cure for, and/or substantial mitigation of,  
5 major diseases, injuries, and orphan diseases.

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

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

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

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

17 S 4. There shall be established within the institute the New York  
18 state stem cell board, hereinafter, the board, which shall govern the  
19 institute and is hereby vested with full power, authority, and jurisdic-  
20 tion over the institute.

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

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

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

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

52 (1) have a documented history in successful stem cell research advoca-  
53 cy;

54 (2) have experience with state and federal legislative processes that  
55 must include some experience with medical legislative approvals of stan-  
56 dards and/or funding;

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

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

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

7 (6) have legal experience with the legal review of proper governmental  
8 authority for the exercise of government agency or government institu-  
9 tional powers;

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

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

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

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

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

18 f. Ensure the completion of an annual financial audit of the insti-  
19 tute's operations.

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

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

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

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

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

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

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

37 (2) the grantees for the prior year;

38 (3) the institute's administrative expenses;

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

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

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

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

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

52 c. Citizen's financial accountability oversight committee. There shall  
53 be a citizen's financial accountability oversight committee chaired by  
54 the state comptroller. This committee shall review the annual financial  
55 audit, the state comptroller's report and evaluation of that audit, and  
56 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.