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2009-2010 Regular Sessions

I N S E N A T E

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Introduced by Sens. PERKINS, DUANE, C. JOHNSON, ONORATO, STAVISKY,
THOMPSON -- 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 may be cited as the "New York Stem
2 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:

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

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

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

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

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

7 c. Funds authorized for, or made available to, the institute shall be
8 continuously appropriated without regard to fiscal year, be available
9 and used only for the purposes provided in this article, and shall not
10 be subject to appropriation or transfer by the legislature or the gover-
11 nor for any other purpose.

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

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

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

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

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

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

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

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

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

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

3 (6) have legal experience with the legal review of proper governmental
4 authority for the exercise of government agency or government institu-
5 tional powers;

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

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

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

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

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

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

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

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

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

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

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

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

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

33 (2) the grantees for the prior year;

34 (3) the institute's administrative expenses;

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

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

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

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

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

48 c. Citizen's financial accountability oversight committee. There shall
49 be a citizen's financial accountability oversight committee chaired by
50 the state comptroller. This committee shall review the annual financial
51 audit, the state comptroller's report and evaluation of that audit, and
52 the financial practices of the institute. The state comptroller, the
53 state treasurer, the president pro tempore of the senate, the speaker of
54 the assembly, and the chairperson of the board shall each appoint a
55 public member of the committee. Committee members shall have medical
56 backgrounds and knowledge of relevant financial matters. The committee

1 shall provide recommendations on the institute's financial practice and
2 performance. The state comptroller shall provide staff support. The
3 committee shall hold a public meeting, with appropriate notice, and with
4 a formal public comment period. The committee shall evaluate public
5 comments and include appropriate summaries in its annual report. The
6 board shall provide funds for the per diem expenses of the committee
7 members and for publication of the annual report.

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

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

19 c. The adoption of standards is not a decision subject to this
20 section.

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

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

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

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

45 S 11. This act shall take effect only in the event that a chapter of
46 the laws of 2009 entitled "AN ACT authorizing the creation of state debt
47 to the amount of one billion dollars; creating the New York stem cell
48 research bond act of 2009, to provide moneys for the development of the
49 New York Stem Cell Research Institute, and providing for the submission
50 to the people of a proposition or question therefor to be voted upon at
51 the general election in November 2009", is approved by the people at the
52 general election to be held in November, 2009. Upon such approval, this
53 act shall take effect immediately. Effective immediately, the addition,
54 amendment, and/or repeal of any rule or regulation necessary for the
55 implementation of the foregoing sections of this act are authorized and
56 directed to be made and completed on or before such effective date.