

107<sup>TH</sup> CONGRESS  
2<sup>D</sup> SESSION

# H. R. 4011

To establish the Stem Cell Research Board to conduct research on the effects of the President's August 9, 2001, stem cell research directive, and for other purposes.

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## IN THE HOUSE OF REPRESENTATIVES

MARCH 20, 2002

Mrs. MALONEY of New York (for herself, Mrs. MORELLA, Mr. LANGEVIN, and Mr. EVANS) introduced the following bill; which was referred to the Committee on Energy and Commerce

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## A BILL

To establish the Stem Cell Research Board to conduct research on the effects of the President's August 9, 2001, stem cell research directive, and for other purposes.

1        *Be it enacted by the Senate and House of Representa-*  
2        *tives of the United States of America in Congress assembled,*

3        **SECTION 1. SHORT TITLE.**

4        This Act may be cited as the “Science of Stem Cell  
5        Research Act”.

6        **SEC. 2. FINDINGS.**

7        The Congress finds as follows:

8            (1) President George W. Bush, after much  
9        thoughtful consideration, decided to move forward

1 with Federal funding for human embryonic stem cell  
2 research on existing stem cell lines.

3 (2) President George W. Bush established the  
4 President's Council on Bioethics, which advises the  
5 President on the ethical significance of emerging bio-  
6 medical science and technology.

7 (3) The principal mission of the President's  
8 Council on Bioethics is to explore the ethical issues  
9 connected with advances in biotechnology.

10 (4) Advances in biomedicine are guiding sci-  
11 entists to improved medical treatments for people  
12 suffering from many debilitating and life-threatening  
13 diseases and injuries, such as Parkinson's disease,  
14 juvenile diabetes, and spinal cord injuries.

15 (5) The advancement of science is paramount  
16 in the alleviation and eradication of diseases and  
17 other medical disorders.

18 (6) There are a finite number of human embry-  
19 onic stem cell lines designated on the Human Em-  
20 bryonic Stem Cell Registry of the National Institutes  
21 of Health. These lines will provide much opportunity  
22 for researching the potential of embryonic stem cells.  
23 However, this number of lines may not be enough to  
24 meet the Nation's research needs.

1           (7) Federal funds are crucial for researchers to  
2 proceed with stem cell research and technologies.

3           (8) The ability to use pluripotent stem cells de-  
4 rived from human embryos provides an opportunity  
5 for doctors to learn to generate specialized cells that  
6 are destroyed or damaged by diseases or disabilities,  
7 such as the dopamine-producing cells that are degen-  
8 erated in Parkinson's disease and the insulin-pro-  
9 ducing cells that are impaired in diabetes.

10          (9) Pluripotent stem cell research could lead to  
11 vastly improved treatments or cures for AIDS, Alz-  
12 heimer's disease, anemia, arthritis, birth defects,  
13 blindness, brain injury, cancer, deafness, diabetes,  
14 heart disease, kidney disease, liver disease, Lou  
15 Gehrig's disease, lung disease, multiple sclerosis,  
16 muscular dystrophy, Parkinson's disease, severe  
17 burns, sickle cell anemia, spinal cord injury, and  
18 stroke, and could also lead to improved success of  
19 organ transplantation.

20          (10) Federal funding through the National In-  
21 stitutes of Health ensures that research will be con-  
22 ducted in accordance with the highest scientific and  
23 ethical standards.

24          (11) According to the National Academy of  
25 Sciences:

1           (A) Current scientific data indicate that  
2           there are important biological differences be-  
3           tween adult and embryonic stem cells and  
4           among adult stem cells found in different types  
5           of tissue. The therapeutic implications of these  
6           biological differences are not clear, and addi-  
7           tional scientific data are needed on all stem cell  
8           types.

9           (B) Over time all cell lines in tissue culture  
10          change, typically accumulating harmful genetic  
11          mutations. Most existing stem cell lines have  
12          been cultured in the presence of nonhuman cells  
13          or serums that could lead to potential human  
14          health risks. Changing genetic and biological  
15          properties of these stem cell lines necessitate  
16          continued monitoring as well as the develop-  
17          ment of new stem cell lines in the future.

18          (C) Human stem cell research that is pub-  
19          licly funded and conducted under the estab-  
20          lished standards of open scientific exchange,  
21          peer review, and public oversight offers the  
22          most efficient and responsible means to fulfill  
23          the promise of stem cells to meet the need for  
24          regenerative medical therapies.

1 **SEC. 3. ESTABLISHMENT.**

2       There is established in the legislative branch a bipar-  
3 tisan commission to be known as the Stem Cell Research  
4 Board (in this Act referred to as the “Board”).

5 **SEC. 4. DUTIES.**

6       (a) RESEARCH.—The Board shall conduct research  
7 on the following:

8           (1) The effects, whether positive or negative, of  
9 the President’s August 9, 2001, stem cell research  
10 directive, on the following:

11           (A) The progress of advances in curing or  
12 remediating diseases or other medical condi-  
13 tions, including AIDS, Alzheimer’s disease, ane-  
14 mia, arthritis, birth defects, blindness, brain in-  
15 jury, cancer, deafness, diabetes, heart disease,  
16 kidney disease, liver disease, Lou Gehrig’s dis-  
17 ease, lung disease, multiple sclerosis, muscular  
18 dystrophy, Parkinson’s disease, severe burns,  
19 sickle cell anemia, spinal cord injury, and  
20 stroke.

21           (B) The progress of improvements in suc-  
22 cessful organ transplantation.

23           (C) The development of any medical tech-  
24 nology, including any halt or delay in such de-  
25 velopment.

26           (D) Basic scientific research.

1           (2) The effect of limiting Federal funding on  
2           the private stem cell research sector.

3           (3) All aspects of the funding process of the  
4           National Institutes of Health for human adult and  
5           embryonic stem cell research.

6           (b) **RECOMMENDATIONS.**—In reports submitted  
7           under section 9, the Board shall make recommendations  
8           to the Congress on any legislation needed to reduce any  
9           inefficiencies in Federal funding of human embryonic stem  
10          cell research or to facilitate a more timely implementation  
11          of such research.

12          (c) **PUBLIC FORUMS.**—The Board shall conduct peri-  
13          odic public forums to review the status of stem cell re-  
14          search funding by the National Institutes of Health.

15          (d) **STANDARDS OF CONDUCT.**—The Board shall de-  
16          velop its own standards of conduct in consultation with  
17          the Committee on Standards of Official Conduct of the  
18          House of Representatives or the Select Committee on Eth-  
19          ics of the Senate, as applicable.

20          **SEC. 5. MEMBERSHIP.**

21          (a) **NUMBER AND APPOINTMENT.**—The Board shall  
22          be composed of 8 members, appointed not later than 120  
23          days after the date of the enactment of this Act. To ensure  
24          that the membership of the Board is bipartisan and sub-

1 ject to subsection (b), the 8 members shall be appointed  
2 as follows:

3 (1) 4 members appointed by the President, the  
4 Speaker of the House of Representatives, and the  
5 minority leader of the Senate as follows:

6 (A) 2 members appointed by the President.

7 (B) 1 member appointed by the Speaker of  
8 the House of Representatives.

9 (C) 1 member appointed by the minority  
10 leader of the Senate.

11 (2) 4 members appointed by the minority leader  
12 of the House of Representatives and the majority  
13 leader of the Senate as follows:

14 (A) 2 members appointed by the minority  
15 leader of the House of Representatives.

16 (B) 2 members appointed by the majority  
17 leader of the Senate.

18 (b) POLITICAL PARTY.—No more than 4 of the mem-  
19 bers of the Board may be appointed by officials of the  
20 same political party.

21 (c) TERMS.—Each member shall be appointed for the  
22 life of the Board.

23 (d) VACANCIES.—A vacancy in the Board shall be  
24 filled in the manner in which the original appointment was  
25 made.

1 (e) BASIC PAY.—

2 (1) RATES OF PAY.—Members shall serve with-  
3 out pay for their service on the Board.

4 (2) TRAVEL EXPENSES.—Members shall receive  
5 travel expenses, including per diem in lieu of subsist-  
6 ence, in accordance with applicable provisions under  
7 subchapter I of chapter 57 of title 5, United States  
8 Code.

9 (f) QUORUM.—Five members of the Board shall con-  
10 stitute a quorum but a lesser number may hold hearings.

11 (g) CO-CHAIRPERSONS.—The Board shall have—

12 (1) a co-chairperson who shall be appointed  
13 jointly by the members appointed under subsection  
14 (a)(1); and

15 (2) a co-chairperson who shall be appointed  
16 jointly by the members appointed under subsection  
17 (a)(2).

18 (h) MEETINGS.—The Board shall meet at the call of  
19 either co-chairperson.

20 (i) REGULATIONS.—The Board may promulgate any  
21 regulations necessary to carry out its duties.

22 **SEC. 6. EXECUTIVE DIRECTORS; STAFF; EXPERTS AND CON-**  
23 **SULTANTS.**

24 (a) EXECUTIVE DIRECTORS.—

25 (1) APPOINTMENT.—The Board shall have—



1 (A) an executive director who shall be ap-  
2 pointed jointly by the members appointed under  
3 section 5(a)(1); and

4 (B) an executive director who shall be ap-  
5 pointed jointly by the members appointed under  
6 section 5(a)(2).

7 (2) PAY.—Each of the executive directors of the  
8 Board shall be paid at a rate not to exceed level IV  
9 of the Executive Schedule.

10 (b) STAFF; EXPERTS.—

11 (1) APPOINTMENT; PAY.—Subject to such rules  
12 as the Board may prescribe, each executive  
13 director—

14 (A) may appoint such additional personnel  
15 as that executive director considers appropriate;  
16 and

17 (B) may procure temporary and intermit-  
18 tent services of experts or consultants at rates  
19 for individuals not to exceed the daily equiva-  
20 lent of the maximum annual rate of pay pay-  
21 able for grade GS–15 of the General Schedule.

22 (2) SHARING OF RESOURCES.—The rules re-  
23 ferred to in paragraph (1) shall include provisions to  
24 ensure an equitable division or sharing of resources,

1 as appropriate, between the respective staffs of the  
2 Board.

3 (c) APPLICABILITY OF CERTAIN CIVIL SERVICE  
4 LAWS.—The executive directors and the staff of the Board  
5 shall not be considered civil service positions in the execu-  
6 tive branch.

7 (d) STAFF OF FEDERAL AGENCIES.—Upon the re-  
8 quest of the Board, the head of any Federal agency may  
9 detail, without reimbursement, any employee of such agen-  
10 cy to the Board to assist the Board in carrying out its  
11 duties. Any such detail shall not interrupt or otherwise  
12 affect the civil service status or privileges of the employee.

13 (e) TECHNICAL ASSISTANCE.—Upon the request of  
14 the Board, the head of a Federal agency shall provide such  
15 technical assistance to the Board as the Board determines  
16 to be necessary to carry out its duties.

17 **SEC. 7. POWERS.**

18 (a) HEARINGS AND SESSIONS.—The Board may, for  
19 the purpose of carrying out this Act, hold hearings (at  
20 the call of either co-chairperson), sit and act at times and  
21 places, take testimony, and receive evidence as the Board  
22 considers appropriate.

23 (b) OATHS OR AFFIRMATIONS.—The Board may ad-  
24 minister oaths or affirmations to witnesses appearing be-  
25 fore it.

1           (c) POWERS OF MEMBERS AND AGENTS.—Any mem-  
2 ber or agent of the Board may, if authorized by the Board,  
3 take any action which the Board is authorized to take by  
4 this section.

5           (d) OBTAINING OFFICIAL DATA.—Subject to sections  
6 552 and 552a of title 5, United States Code, the Board  
7 or the co-chairpersons of the Board acting jointly may se-  
8 cure directly from any other Federal agency all informa-  
9 tion that the Board considers necessary to enable the  
10 Board to carry out its duties. Upon request of the Board  
11 or both co-chairpersons, the head of that agency (or other  
12 person duly designated for purposes of this subsection)  
13 shall furnish that information to the Board.

14           (e) MAILS.—The Board may use the United States  
15 mails in the same manner and under the same conditions  
16 as Federal agencies and shall, for purposes of the frank,  
17 be considered a commission of the Congress as described  
18 in section 3215 of title 39, United States Code.

19           (f) ADMINISTRATIVE SUPPORT SERVICES.—The Pub-  
20 lic Printer of the Government Printing Office shall provide  
21 to the Board on a reimbursable basis such administrative  
22 support services, including accounting services, as the  
23 Board may request.

24           (g) OFFICE SPACE.—The Administrator of General  
25 Services, in coordination with the Secretary of Health and

1 Human Services, shall locate suitable office space for the  
2 operation of the Board at the National Institutes of  
3 Health campus in Bethesda, Maryland. The facilities shall  
4 serve as the headquarters of the Board and shall include  
5 all necessary equipment and incidentals required for the  
6 proper functioning of the Board.

7 (h) ADVICE AND ASSISTANCE OF OTHER FEDERAL  
8 EXECUTIVE AGENCIES.—The Board or members of the  
9 Board may seek the advice of the National Science Foun-  
10 dation, the National Academy of Sciences, or any Federal  
11 executive agency with expertise in stem cell research. The  
12 National Science Foundation, the National Academy of  
13 Sciences, and any such Federal executive agency shall, if  
14 requested, provide assistance to the Board.

15 (i) PRINTING AND BINDING.—For purposes of costs  
16 relating to printing and binding, including the cost of per-  
17 sonnel detailed from the Government Printing Office, the  
18 Board shall be deemed to be a committee of the Congress.

19 (j) DISCLOSURE OF INFORMATION TO CONGRESS.—  
20 Any data or other information obtained by the Board  
21 under this section shall be made available to any com-  
22 mittee or subcommittee of the Congress of appropriate ju-  
23 risdiction upon request of the chairperson or ranking mi-  
24 nority member of such committee or subcommittee.

1 (k) CONTRACT AUTHORITY.—To the extent or in the  
2 amounts provided in advance in appropriation Acts, the  
3 Board may contract with and compensate government and  
4 private agencies or persons for supplies and other services.

5 **SEC. 8. AUDITS.**

6 (a) IN GENERAL.—The Public Printer shall  
7 conduct—

8 (1) an interim audit of the financial trans-  
9 actions of the Board not later than 2 years after the  
10 date of the enactment of this Act; and

11 (2) a final audit of the financial transactions of  
12 the Board not later than 4 years after the date of  
13 the enactment of this Act.

14 (b) ACCESS.—The Board shall maintain records of  
15 its financial transactions and shall ensure that the Public  
16 Printer has access to all such records, and to property in  
17 use by the Board, as necessary to facilitate an audit under  
18 subsection (a).

19 **SEC. 9. REPORTS.**

20 In accordance with section 4(b), the Board shall  
21 transmit to the Congress—

22 (1) an interim report each year; and

23 (2) not later than the date of the Board's ter-  
24 mination under section 10, a final report containing  
25 a detailed statement of the findings and conclusions

1 of the Board with respect to the matters described  
2 in section 4.

3 **SEC. 10. TERMINATION.**

4 (a) IN GENERAL.—The Board shall terminate on the  
5 date that is 4 years after the date of the enactment of  
6 this Act.

7 (b) TRANSFER OF RECORDS.—Upon the termination  
8 of the Board under this section, the Board shall transfer  
9 all of its records to the Public Printer.

10 **SEC. 11. AUTHORIZATION OF APPROPRIATIONS.**

11 There is authorized to be appropriated to the Board  
12 \$16,000,000 to carry out this Act.

○