

107TH CONGRESS  
1ST SESSION

# H. R. 2096

To provide for a National Stem Cell Donor Bank regarding qualifying human stem cells, and for the conduct and support of research using such cells.

---

## IN THE HOUSE OF REPRESENTATIVES

JUNE 7, 2001

Mr. SMITH of New Jersey (for himself, Mr. ADERHOLT, Mr. BACHUS, Mr. BAKER, Mr. BARCIA, Mr. BLUNT, Mr. BRYANT, Mr. CAMP, Mr. COSTELLO, Mr. DEMINT, Mr. DOOLITTLE, Mr. GREEN of Wisconsin, Ms. HART, Mr. HOEKSTRA, Mr. HOLDEN, Mr. LANGEVIN, Mr. LARGENT, Mr. LEWIS of Kentucky, Mr. LIPINSKI, Mr. PENCE, Mr. PHELPS, Mr. PICKERING, Mr. PITTS, Mr. RAHALL, Mr. ROHRABACHER, Mr. RYUN of Kansas, Mr. SCHROCK, Mr. SHADEGG, Mr. SHIMKUS, Mr. SHOWS, Mr. SOUDER, Mr. STUMP, Mr. TANCREDO, Mr. TIAHRT, Mr. VITTER, Mr. WICKER, Mr. THUNE, Mrs. MYRICK, and Mr. STEARNS) introduced the following bill; which was referred to the Committee on Energy and Commerce

---

## A BILL

To provide for a National Stem Cell Donor Bank regarding qualifying human stem cells, and for the conduct and support of research using such cells.

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 “Responsible Stem Cell  
5 Research Act of 2001”.

1 **SEC. 2. FINDINGS.**

2 The Congress finds as follows:

3 (1) Past investments in biomedical research  
4 have resulted in better health, an improved quality  
5 of life for all Americans, and a reduction in national  
6 health care expenditures.

7 (2) The Nation's commitment to biomedical re-  
8 search has expanded the base of scientific knowledge  
9 about health and disease and revolutionized the  
10 practice of medicine.

11 (3) Research sponsored by the National Insti-  
12 tutes of Health is responsible for the identification  
13 of genetic mutations relating to nearly 100 diseases,  
14 including Alzheimer's disease, cystic fibrosis, Hun-  
15 tington's disease, osteoporosis, many forms of can-  
16 cer, and immune deficiency disorders.

17 (4) Many Americans still face serious and life-  
18 threatening health problems, both acute and chronic.

19 (5) Neurodegenerative diseases of the elderly,  
20 such as Alzheimer's and Parkinson's disease, threat-  
21 en to destroy the lives of millions of Americans.

22 (6) Cancer remains a comprehensive threat to  
23 any tissue or organ of the body at any age, and re-  
24 mains a leading cause of morbidity and mortality.

25 (7) The extent of psychiatric and neurological  
26 diseases poses considerable challenges in under-

1 standing the workings of the brain and nervous sys-  
2 tem.

3 (8) Diabetes, both insulin and noninsulin forms,  
4 afflicts 16 million Americans and places them at risk  
5 for acute and chronic complications, including blind-  
6 ness, kidney failure, atherosclerosis, and nerve de-  
7 generation.

8 (9) Recent scientific developments show that  
9 human stem cell research based on ethically respon-  
10 sible stem cell sources may lead to exponential im-  
11 provements in the treatment of many terminal and  
12 debilitating conditions, from cancer to Parkinson's  
13 to Alzheimer's to diabetes to heart disease.

14 (10) To take full advantage of the tremendous  
15 potential for finding a cure or effective treatment for  
16 many debilitating diseases, the Federal investment  
17 in ethical stem cell research must be expanded.

18 **SEC. 3. NATIONAL STEM CELL DONOR BANK.**

19 (a) IN GENERAL.—The Secretary of Health and  
20 Human Services shall by contract establish and maintain  
21 a National Stem Cell Donor Bank (in this section referred  
22 to as the “Donor Bank”). The purpose of the Donor Bank  
23 shall be to seek and preserve donations of qualifying  
24 human stem cells and to make such donated cells available  
25 for biomedical research and for therapeutic purposes.

1       (b) QUALIFYING HUMAN STEM CELLS.—For pur-  
2 poses of this Act, the term “qualifying human stem cells”  
3 means human stem cells obtained from human placentas,  
4 umbilical cord blood, organs or tissues of a living or de-  
5 ceased human being who has been born, or organs or tis-  
6 sues of unborn human offspring who died of natural  
7 causes (such as spontaneous abortion).

8       (c) ADMINISTRATION OF DONOR BANK.—The Donor  
9 Bank shall be under the general supervision of the Sec-  
10 retary, and under the direction of a board of directors  
11 meeting such criteria as the Secretary may establish.

12       (d) PATIENT REGISTRY.—The Donor Bank shall  
13 with respect to qualifying human stem cells—

14               (1) operate a registry of patients who are trans-  
15 plant candidates;

16               (2) establish a system for finding donors who  
17 are unrelated to the candidate patients and are suit-  
18 ably matched to the patients; and

19               (3) carry out informational and educational ac-  
20 tivities.

21       (e) CRITERIA.—The Secretary shall establish criteria  
22 for the Donor Bank and other entities that participate in  
23 the program under this section, including—

24               (1) quality standards and standards for tissue  
25 typing and obtaining the informed consent of do-

1       nors, or the parents or legal representatives of do-  
2       nors as appropriate;

3           (2) donor selection criteria, based on estab-  
4       lished medical criteria, to protect both donors and  
5       transplant recipients and to prevent the trans-  
6       mission of potentially harmful infectious diseases;

7           (3) procedures to ensure the proper collection  
8       and transportation of qualifying human stem cells;  
9       and

10       (4) standards that—

11           (A) require the establishment of a system  
12       of strict confidentiality of records relating to  
13       the identity and address of and medical infor-  
14       mation on patients and donors; and

15           (B) prescribe the purposes for which the  
16       records described in subparagraph (A) may be  
17       disclosed, and the circumstances and extent of  
18       the disclosure.

19       (f) AUTHORIZATION OF APPROPRIATIONS.—For the  
20       purpose of carrying out this section, there are authorized  
21       to be appropriated such sums as may be necessary for  
22       each of the fiscal years 2002 through 2006.

1 **SEC. 4. USE OF QUALIFYING HUMAN STEM CELLS IN RE-**  
2 **SEARCH CONDUCTED OR SUPPORTED BY NA-**  
3 **TIONAL INSTITUTES OF HEALTH.**

4 (a) IN GENERAL.—The Secretary, acting through the  
5 Director of the National Institutes of Health, may conduct  
6 and support research that uses qualifying human stem  
7 cells.

8 (b) AUTHORIZATION OF APPROPRIATIONS.—For the  
9 purpose of carrying out subsection (a), there are author-  
10 ized to be appropriated \$30,000,000 for fiscal year 2002,  
11 and such sums as may be necessary for each of the fiscal  
12 years 2003 through 2006.

13 **SEC. 5. DEFINITIONS.**

14 For purposes of this Act:

15 (1) The term “qualifying human stem cells”  
16 has the meaning given such term in section 3.

17 (2) The term “Secretary” means the Secretary  
18 of Health and Human Services.

○