

Calendar No. 535110TH CONGRESS
1ST SESSION**S. 911**

To amend the Public Health Service Act to advance medical research and treatments into pediatric cancers, ensure patients and families have access to the current treatments and information regarding pediatric cancers, establish a population-based national childhood cancer database, and promote public awareness of pediatric cancers.

IN THE SENATE OF THE UNITED STATES

MARCH 19, 2007

Mr. REED (for himself, Mr. COLEMAN, Mr. HAGEL, Mr. CHAMBLISS, Mr. LUGAR, Mr. ISAKSON, Mr. BUNNING, Mr. GRAHAM, Ms. STABENOW, Mr. WHITEHOUSE, Mr. LAUTENBERG, Mr. KERRY, Mr. BROWN, Mr. CARPER, Mr. JOHNSON, Mr. WYDEN, Mr. McCONNELL, Mr. BAYH, Mr. LIEBERMAN, Mrs. FEINSTEIN, Mr. COCHRAN, Mr. CORNYN, Mrs. BOXER, Mrs. CLINTON, Mr. CARDIN, Mr. SANDERS, Mr. AKAKA, Mr. BINGAMAN, Mr. SCHUMER, Mr. INOUE, Mr. MENENDEZ, Mr. DOMENICI, Mr. BURR, Mr. LEAHY, Mr. CASEY, Ms. KLOBUCHAR, Mr. PRYOR, Ms. MIKULSKI, Mr. KENNEDY, Ms. LANDRIEU, Mr. BIDEN, Mr. REID, Mr. DODD, Mrs. LINCOLN, and Mrs. MURRAY) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

DECEMBER 12, 2007

Reported by Mr. KENNEDY, with an amendment

[Strike out all after the enacting clause and insert the part printed in italic]

A BILL

To amend the Public Health Service Act to advance medical research and treatments into pediatric cancers, ensure patients and families have access to the current treat-

ments and information regarding pediatric cancers, establish a population-based national childhood cancer database, and promote public awareness of pediatric cancers.

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 “Conquer Childhood
 5 Cancer Act of 2007”.

6 **SEC. 2. FINDINGS.**

7 Congress makes the following findings:

8 (1) Cancer kills more children than any other
 9 disease.

10 (2) Each year cancer kills more children be-
 11 tween 1 and 20 years of age than asthma, diabetes,
 12 cystic fibrosis, and AIDS, combined.

13 (3) Every year, over 12,500 young people are
 14 diagnosed with cancer.

15 (4) Each year about 2,300 children and teen-
 16 agers die from cancer.

17 (5) One in every 330 Americans develops cancer
 18 before age 20.

19 (6) Some forms of childhood cancer have proven
 20 to be so resistant that even in spite of the great re-
 21 search strides made, most of those children die. Up

1 to 75 percent of the children with cancer can now
2 be cured.

3 (7) The causes of most childhood cancers are
4 not yet known.

5 (8) Childhood cancers are mostly those of the
6 white blood cells (leukemias), brain, bone, the lym-
7 phatic system, and tumors of the muscles, kidneys,
8 and nervous system. Each of these behaves dif-
9 ferently, but all are characterized by an uncontrolled
10 proliferation of abnormal cells.

11 (9) Eighty percent of the children who are diag-
12 nosed with cancer have disease which has already
13 spread to distant sites in the body.

14 (10) Ninety percent of children with a form of
15 pediatric cancer are treated at one of the more than
16 200 Children's Oncology Group member institutions
17 throughout the United States.

18 **SEC. 3. PURPOSES.**

19 It is the purpose of this Act to authorize appropria-
20 tions to—

21 (1) encourage and expand the support for bio-
22 medical research programs of the existing National
23 Cancer Institute-designated multicenter national in-
24 frastructure for pediatric cancer research;

1 (2) establish a population-based national child-
 2 hood cancer database (the Children’s Cancer Re-
 3 search Network) to evaluate incidence trends of
 4 childhood cancers and to enable the investigations of
 5 genetic epidemiology in order to identify causes to
 6 aid in development of prevention strategies;

7 (3) provide informational services to patients
 8 and families affected by childhood cancer;

9 (4) support the development, construction, and
 10 operation of a comprehensive online public informa-
 11 tion system on childhood cancers and services avail-
 12 able to families; and

13 (5) establish a fellowship program in pediatric
 14 cancer research to foster clinical and translational
 15 research career development in pediatric oncologists
 16 in the early stages of their career.

17 **SEC. 4. PEDIATRIC CANCER RESEARCH AND AWARENESS.**

18 Subpart 1 of part C of title IV of the Public Health
 19 Service Act (42 U.S.C. 285 et seq.) is amended by adding
 20 at the end the following:

21 **“SEC. 417E. PEDIATRIC CANCER RESEARCH AND AWARE-**
 22 **NESS.**

23 “(a) PEDIATRIC CANCER RESEARCH.—

24 “(1) SPECIAL PROGRAMS OF RESEARCH EXCEL-
 25 LENCE IN PEDIATRIC CANCERS.—The Director of

1 NHH, acting through the National Cancer Institute,
2 shall establish special programs of research excel-
3 lence in the area of pediatric cancers. Such pro-
4 grams shall demonstrate a balanced approach to re-
5 search cause, prognosis, prevention, diagnosis, and
6 treatment of pediatric cancers that foster translation
7 of basic research findings into innovative interven-
8 tions applied to patients.

9 “(2) FELLOWSHIP OF EXCELLENCE IN PEDI-
10 ATRIC CANCER RESEARCH.—The Secretary shall de-
11 velop a grant mechanism for the establishment, in
12 cooperation with the National Cancer Institute-sup-
13 ported pediatric cancer clinical trial groups, of Re-
14 search Fellowships in Pediatric Cancer to support
15 adequate numbers of pediatric focused clinical and
16 translational investigators thereby facilitating con-
17 tinuous momentum of research excellence.

18 “(b) NATIONAL CHILDHOOD CANCER REGISTRY.—
19 The Director of NHH shall award a grant for the operation
20 of a population-based national childhood cancer database,
21 the Childhood Cancer Research Network (CCRN), of the
22 Children’s Oncology Group, in cooperation with the Na-
23 tional Cancer Institute.

24 “(c) PUBLIC AWARENESS OF PEDIATRIC CANCERS
25 AND AVAILABLE TREATMENTS AND RESEARCH.—The

1 Secretary shall award grants to recognized childhood can-
 2 cer professional and advocacy organizations for the expan-
 3 sion and widespread implementation of activities to raise
 4 public awareness of currently available information; treat-
 5 ment; and research with the intent to ensure access to best
 6 available therapies for pediatric cancers.

7 “(d) **AUTHORIZATION OF APPROPRIATIONS.**—There
 8 are authorized to be appropriated to carry out this section,
 9 \$30,000,000 for each of fiscal years 2008 through 2012.
 10 Funds appropriated under this section shall remain avail-
 11 able until expended.”.

12 **SECTION 1. SHORT TITLE.**

13 *This Act may be cited as the “Conquer Childhood Can-
 14 cer Act of 2007”.*

15 **SEC. 2. FINDINGS.**

16 *Congress makes the following findings:*

17 (1) *Cancer kills more children than any other
 18 disease.*

19 (2) *Each year cancer kills more children between
 20 1 and 20 years of age than asthma, diabetes, cystic
 21 fibrosis, and AIDS, combined.*

22 (3) *Every year, over 12,500 young people are di-
 23 agnosed with cancer.*

24 (4) *Each year about 2,300 children and teen-
 25 agers die from cancer.*

1 (5) *One in every 330 Americans develops cancer*
2 *before age 20.*

3 (6) *Some forms of childhood cancer have proven*
4 *to be so resistant that even in spite of the great re-*
5 *search strides made, most of those children die. Up to*
6 *75 percent of the children with cancer can now be*
7 *cured.*

8 (7) *The causes of most childhood cancers are not*
9 *yet known.*

10 (8) *Childhood cancers are mostly those of the*
11 *white blood cells (leukemias), brain, bone, the lym-*
12 *phatic system, and tumors of the muscles, kidneys,*
13 *and nervous system. Each of these behaves differently,*
14 *but all are characterized by an uncontrolled prolifera-*
15 *tion of abnormal cells.*

16 (9) *Eighty percent of the children who are diag-*
17 *nosed with cancer have disease which has already*
18 *spread to distant sites in the body.*

19 (10) *Ninety percent of children with a form of*
20 *pediatric cancer are treated at 1 of the more than 200*
21 *Children's Oncology Group member institutions*
22 *throughout the United States.*

1 **SEC. 3. PEDIATRIC CANCER RESEARCH AND AWARENESS;**
 2 **NATIONAL CHILDHOOD CANCER REGISTRY.**

3 (a) *PEDIATRIC CANCER RESEARCH AND AWARE-*
 4 *NESS.*—*Subpart 1 of part C of title IV of the Public Health*
 5 *Service Act (42 U.S.C. 285 et seq.) is amended by adding*
 6 *at the end the following:*

7 **“SEC. 417E. PEDIATRIC CANCER RESEARCH AND AWARE-**
 8 **NESS.**

9 “(a) *PEDIATRIC CANCER RESEARCH.*—

10 “(1) *PROGRAMS OF RESEARCH EXCELLENCE IN*
 11 *PEDIATRIC CANCER.*—*The Secretary, acting through*
 12 *the Director of NIH, in collaboration with other Fed-*
 13 *eral agencies with interest in prevention and treat-*
 14 *ment of pediatric cancer, shall enhance, expand, and*
 15 *intensify pediatric cancer research, including thera-*
 16 *peutically applicable research to generate effective*
 17 *treatments, pediatric preclinical testing, and pedi-*
 18 *atric clinical trials through National Cancer Insti-*
 19 *tute-supported pediatric cancer clinical trial groups*
 20 *and their member institutions. For purposes of this*
 21 *section, the term ‘pediatric cancer research’ means re-*
 22 *search on the causes, prevention, diagnosis, recogni-*
 23 *tion, treatment, and long-term effects of pediatric*
 24 *cancer.*

25 “(2) *FELLOWSHIP OF EXCELLENCE IN PEDIATRIC*
 26 *CANCER RESEARCH.*—*The Secretary, acting through*

1 *the Director of NIH, shall award grants to enhance*
2 *and expand cancer research fellowships to train and*
3 *develop clinical investigators focused on pediatric*
4 *cancer research.*

5 *“(3) PEER REVIEW REQUIREMENTS.—All grants*
6 *awarded under this subsection shall be awarded in ac-*
7 *cordance with section 492.*

8 *“(b) PUBLIC AWARENESS OF PEDIATRIC CANCERS AND*
9 *AVAILABLE TREATMENTS AND RESEARCH.—*

10 *“(1) IN GENERAL.—The Secretary may award*
11 *grants to childhood cancer professional and direct*
12 *service organizations for the expansion and wide-*
13 *spread implementation of—*

14 *“(A) activities that provide available infor-*
15 *mation on treatment protocols to ensure early*
16 *access to the best available therapies and clinical*
17 *trials for pediatric cancers;*

18 *“(B) activities that provide available infor-*
19 *mation on the late effects of pediatric cancer*
20 *treatment to ensure access to necessary long-term*
21 *medical and psychological care; and*

22 *“(C) direct resource services such as edu-*
23 *cational outreach for parents, peer-to-peer and*
24 *parent-to-parent support networks, information*
25 *on school re-entry and postsecondary education,*

1 *and resource directories or referral services for fi-*
 2 *nancial assistance, psychological counseling, and*
 3 *other support services.*

4 “(2) *PERFORMANCE MEASUREMENT, TRANS-*
 5 *PARENCY, AND ACCOUNTABILITY.—For each grant*
 6 *awarded under this subsection, the Secretary shall de-*
 7 *velop and implement metrics-based performance*
 8 *measures to assess the effectiveness of activities funded*
 9 *under such grant.*

10 “(c) *AUTHORIZATION OF APPROPRIATIONS.—For pur-*
 11 *poses of carrying out this section and section 399E–1, there*
 12 *are authorized to be appropriated \$30,000,000 for each of*
 13 *fiscal years 2008 through 2012. Such authorization of ap-*
 14 *propriations is in addition to the authorization of appro-*
 15 *priations established in section 402A with respect to such*
 16 *purpose. Funds appropriated under this subsection shall re-*
 17 *main available until expended.”.*

18 (b) *NATIONAL CHILDHOOD CANCER REGISTRY.—Part*
 19 *M of title III of the Public Health Service Act (42 U.S.C.*
 20 *280e et seq.) is amended—*

21 (1) *by inserting after section 399E the following:*

22 **“SEC. 399E–1. NATIONAL CHILDHOOD CANCER REGISTRY.**

23 “(a) *IN GENERAL.—The Secretary, acting through the*
 24 *Director of the Centers for Disease Control and Prevention,*
 25 *shall award a grant to enhance and expand infrastructure*

1 *to track the epidemiology of pediatric cancer into a com-*
2 *prehensive nationwide registry of actual occurrences of pe-*
3 *diatric cancer. Such registry shall be updated to include*
4 *an actual occurrence within weeks of the date of such occur-*
5 *rence.*

6 “(b) *INFORMED CONSENT AND PRIVACY REQUIRE-*
7 *MENTS AND COORDINATION WITH EXISTING PROGRAMS.—*
8 *The registry established pursuant to subsection (a) shall be*
9 *subject to section 552a of title 5, United States Code, the*
10 *regulations promulgated under section 264(c) of the Health*
11 *Insurance Portability and Accountability Act of 1996, ap-*
12 *plicable Federal and State informed consent regulations,*
13 *any other Federal laws relating to the privacy of patient*
14 *information, and section 399B(d)(4) of this Act.”; and*
15 (2) *in section 399F(a), by inserting “(other than*
16 *section 399E–1)” after “this part”.*

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