

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

# H. R. 1553

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## AN ACT

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

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 “Caroline Pryce Walker  
5 Conquer Childhood Cancer Act of 2008”.

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  
22 to 75 percent of the children with cancer can now  
23 be cured.

24           (7) The causes of most childhood cancers are  
25 not yet known.

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

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

10           (10) Ninety percent of children with a form of  
11 pediatric cancer are treated at one of the more than  
12 200 Children’s Oncology Group member institutions  
13 throughout the United States.

14 **SEC. 3. PURPOSES.**

15       It is the purpose of this Act to authorize appropria-  
16 tions to—

17           (1) encourage the support for pediatric cancer  
18 research and other activities related to pediatric can-  
19 cer;

20           (2) establish a comprehensive national child-  
21 hood cancer registry; and

22           (3) provide informational services to patients  
23 and families affected by childhood cancer.

1 **SEC. 4. 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  
5 Health Service Act (42 U.S.C. 285 et seq.) is amended  
6 by adding 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, in collabora-  
12 tion with the Director of NIH and other Federal  
13 agencies with interest in prevention and treatment of  
14 pediatric cancer, shall continue to enhance, expand,  
15 and intensify pediatric cancer research and other ac-  
16 tivities related to pediatric cancer, including thera-  
17apeutically applicable research to generate effective  
18 treatments, pediatric preclinical testing, and pedi-  
19atric clinical trials through National Cancer Insti-  
20tute-supported pediatric cancer clinical trial groups  
21 and their member institutions. In enhancing, ex-  
22panding, and intensifying such research and other  
23 activities, the Secretary is encouraged to take into  
24 consideration the application of such research and  
25 other activities for minority, health disparity, and  
26 medically underserved communities. For purposes of

1 this section, the term ‘pediatric cancer research’  
2 means research on the causes, prevention, diagnosis,  
3 recognition, treatment, and long-term effects of pedi-  
4 atric cancer.

5 “(2) PEER REVIEW REQUIREMENTS.—All  
6 grants awarded under this subsection shall be  
7 awarded in accordance with section 492.

8 “(b) PUBLIC AWARENESS OF PEDIATRIC CANCERS  
9 AND 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 clin-  
17 ical 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-  
21 term 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  
2           financial assistance, psychological counseling,  
3           and other support services.

4           In awarding grants under this paragraph, the Sec-  
5           retary is encouraged to take into consideration the  
6           extent to which an entity would use such grant for  
7           purposes of making activities and services described  
8           in this paragraph available to minority, health dis-  
9           parity, and medically underserved communities.

10           “(2) PERFORMANCE MEASUREMENT, TRANS-  
11           PARENCY, AND ACCOUNTABILITY.—For each grant  
12           awarded under this subsection, the Secretary shall  
13           develop and implement metrics-based performance  
14           measures to assess the effectiveness of activities  
15           funded under such grant.

16           “(3) INFORMATIONAL REQUIREMENTS.—Any  
17           information made available pursuant to a grant  
18           awarded under paragraph (1) shall be—

19                   “(A) culturally and linguistically appro-  
20                   priate as needed by patients and families af-  
21                   fected by childhood cancer; and

22                   “(B) approved by the Secretary.

23           “(c) RULE OF CONSTRUCTION.—Nothing in this sec-  
24           tion shall be construed as being inconsistent with the goals  
25           and purposes of the Minority Health and Health Dispari-

1 ties Research and Education Act of 2000 (42 U.S.C. 202  
2 note).

3 “(d) AUTHORIZATION OF APPROPRIATIONS.—For  
4 purposes of carrying out this section and section 399E–  
5 1, there are authorized to be appropriated \$30,000,000  
6 for each of fiscal years 2009 through 2013. Such author-  
7 ization of appropriations is in addition to the authoriza-  
8 tion of appropriations established in section 402A with re-  
9 spect to such purpose. Funds appropriated under this sub-  
10 section shall remain available until expended.”.

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

14 (1) by inserting after section 399E the fol-  
15 lowing:

16 **“SEC. 399E-1. NATIONAL CHILDHOOD CANCER REGISTRY.**

17 “(a) IN GENERAL.—The Secretary, acting through  
18 the Director of the Centers for Disease Control and Pre-  
19 vention, shall award a grant to enhance and expand infra-  
20 structure to track the epidemiology of pediatric cancer into  
21 a comprehensive nationwide registry of actual occurrences  
22 of pediatric cancer. Such registry shall be updated to in-  
23 clude an actual occurrence within weeks of the date of  
24 such occurrence.

1       “(b) INFORMED CONSENT AND PRIVACY REQUIRE-  
2 MENTS AND COORDINATION WITH EXISTING PRO-  
3 GRAMS.—The registry established pursuant to subsection  
4 (a) shall be subject to section 552a of title 5, United  
5 States Code, the regulations promulgated under section  
6 264(e) of the Health Insurance Portability and Account-  
7 ability Act of 1996, applicable Federal and State informed  
8 consent regulations, any other applicable Federal and  
9 State laws relating to the privacy of patient information,  
10 and section 399B(d)(4) of this Act.”; and

11               (2) in section 399F(a), by inserting “(other  
12 than section 399E–1)” after “this part”.

Passed the House of Representatives June 12, 2008.

Attest:

*Clerk.*



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