

One Hundred Tenth Congress
of the
United States of America

AT THE SECOND SESSION

*Begun and held at the City of Washington on Thursday,
the third day of January, two thousand and eight*

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.

*Be it enacted by the Senate and House of Representatives of
the United States of America in Congress assembled,*

SECTION 1. SHORT TITLE.

This Act may be cited as the “Caroline Pryce Walker Conquer Childhood Cancer Act of 2008”.

SEC. 2. FINDINGS.

Congress makes the following findings:

- (1) Cancer kills more children than any other disease.
- (2) Each year cancer kills more children between 1 and 20 years of age than asthma, diabetes, cystic fibrosis, and AIDS, combined.
- (3) Every year, over 12,500 young people are diagnosed with cancer.
- (4) Each year about 2,300 children and teenagers die from cancer.
- (5) One in every 330 Americans develops cancer before age 20.
- (6) Some forms of childhood cancer have proven to be so resistant that even in spite of the great research strides made, most of those children die. Up to 75 percent of the children with cancer can now be cured.
- (7) The causes of most childhood cancers are not yet known.
- (8) Childhood cancers are mostly those of the white blood cells (leukemias), brain, bone, the lymphatic system, and tumors of the muscles, kidneys, and nervous system. Each of these behaves differently, but all are characterized by an uncontrolled proliferation of abnormal cells.
- (9) Eighty percent of the children who are diagnosed with cancer have disease which has already spread to distant sites in the body.
- (10) Ninety percent of children with a form of pediatric cancer are treated at one of the more than 200 Children’s Oncology Group member institutions throughout the United States.

SEC. 3. PURPOSES.

It is the purpose of this Act to authorize appropriations to—

- (1) encourage the support for pediatric cancer research and other activities related to pediatric cancer;
- (2) establish a comprehensive national childhood cancer registry; and
- (3) provide informational services to patients and families affected by childhood cancer.

SEC. 4. PEDIATRIC CANCER RESEARCH AND AWARENESS; NATIONAL CHILDHOOD CANCER REGISTRY.

(a) PEDIATRIC CANCER RESEARCH AND AWARENESS.—Subpart 1 of part C of title IV of the Public Health Service Act (42 U.S.C. 285 et seq.) is amended by adding at the end the following:

“SEC. 417E. PEDIATRIC CANCER RESEARCH AND AWARENESS.

“(a) PEDIATRIC CANCER RESEARCH.—

“(1) PROGRAMS OF RESEARCH EXCELLENCE IN PEDIATRIC CANCER.—The Secretary, in collaboration with the Director of NIH and other Federal agencies with interest in prevention and treatment of pediatric cancer, shall continue to enhance, expand, and intensify pediatric cancer research and other activities related to pediatric cancer, including therapeutically applicable research to generate effective treatments, pediatric preclinical testing, and pediatric clinical trials through National Cancer Institute-supported pediatric cancer clinical trial groups and their member institutions. In enhancing, expanding, and intensifying such research and other activities, the Secretary is encouraged to take into consideration the application of such research and other activities for minority, health disparity, and medically underserved communities. For purposes of this section, the term ‘pediatric cancer research’ means research on the causes, prevention, diagnosis, recognition, treatment, and long-term effects of pediatric cancer.

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

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

“(1) IN GENERAL.—The Secretary may award grants to childhood cancer professional and direct service organizations for the expansion and widespread implementation of—

“(A) activities that provide available information on treatment protocols to ensure early access to the best available therapies and clinical trials for pediatric cancers;

“(B) activities that provide available information on the late effects of pediatric cancer treatment to ensure access to necessary long-term medical and psychological care; and

“(C) direct resource services such as educational outreach for parents, peer-to-peer and parent-to-parent support networks, information on school re-entry and postsecondary education, and resource directories or referral services for financial assistance, psychological counseling, and other support services.

In awarding grants under this paragraph, the Secretary is encouraged to take into consideration the extent to which an entity would use such grant for purposes of making activities and services described in this paragraph available to minority, health disparity, and medically underserved communities.

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

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

“(A) culturally and linguistically appropriate as needed by patients and families affected by childhood cancer; and

“(B) approved by the Secretary.

“(c) RULE OF CONSTRUCTION.—Nothing in this section shall be construed as being inconsistent with the goals and purposes of the Minority Health and Health Disparities Research and Education Act of 2000 (42 U.S.C. 202 note).

“(d) AUTHORIZATION OF APPROPRIATIONS.—For purposes of carrying out this section and section 399E–1, there are authorized to be appropriated \$30,000,000 for each of fiscal years 2009 through 2013. Such authorization of appropriations is in addition to the authorization of appropriations established in section 402A with respect to such purpose. Funds appropriated under this subsection shall remain available until expended.”

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

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

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

“(a) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall award a grant to enhance and expand infrastructure to track the epidemiology of pediatric cancer into a comprehensive nationwide registry of actual occurrences of pediatric cancer. Such registry shall be updated to include an actual occurrence within weeks of the date of such occurrence.

“(b) INFORMED CONSENT AND PRIVACY REQUIREMENTS AND COORDINATION WITH EXISTING PROGRAMS.—The registry established pursuant to subsection (a) shall be subject to section 552a of title 5, United States Code, the regulations promulgated under section 264(c) of the Health Insurance Portability and Accountability Act of 1996, applicable Federal and State informed consent regulations, any other applicable Federal and State laws relating to the privacy of patient information, and section 399B(d)(4) of this Act.”; and

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

Speaker of the House of Representatives.

*Vice President of the United States and
President of the Senate.*