

CAROLINE PRYCE WALKER CONQUER CHILDHOOD  
 CANCER ACT OF 2008

JUNE 10, 2008.—Committed to the Committee of the Whole House on the State of  
 the Union and ordered to be printed

Mr. DINGELL, from the Committee on Energy and Commerce,  
 submitted the following

R E P O R T

[To accompany H.R. 1553]

[Including cost estimate of the Congressional Budget Office]

The Committee on Energy and Commerce, to whom was referred the bill (H.R. 1553) 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, having considered the same, report favorably thereon with amendments and recommend that the bill as amended do pass.

CONTENTS

	Page
Amendments .....	2
Purpose and Summary .....	3
Background and Need for Legislation .....	4
Hearings .....	4
Committee Consideration .....	4
Committee Votes .....	4
Committee Oversight Findings .....	4
Statement of General Performance Goals and Objectives .....	5
New Budget Authority, Entitlement Authority, and Tax Expenditures .....	5
Earmarks and Tax and Tariff Benefits .....	5
Committee Cost Estimate .....	5
Congressional Budget Office Estimate .....	5
Federal Mandates Statement .....	7
Advisory Committee Statement .....	7
Constitutional Authority Statement .....	7
Applicability to Legislative Branch .....	7
Section-by-Section Analysis of the Legislation .....	7

## AMENDMENTS

The amendments are as follows:

Strike all after the enacting clause and insert the following:

**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.

“(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

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

Amend the title so as to read:

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 information regarding pediatric cancers and current treatments for such cancers, establish a national childhood cancer registry, and promote public awareness of pediatric cancer.

#### PURPOSE AND SUMMARY

The purpose of H.R. 1553, the “Caroline Pryce Walker Conquer Childhood Cancer Act of 2008”, is 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 cancers.

#### BACKGROUND AND NEED FOR LEGISLATION

Between infancy and 15 years of age, cancer is the leading cause of death by disease among U.S. children. In 2007, approximately 10,400 new cases of pediatric cancer were diagnosed in children ages 0 to 14 years. Although the incidence of invasive cancer in children has increased slightly over the past 30 years, mortality has declined dramatically for many childhood cancers. The combined 5-year survival rate for all childhood cancers has improved from less than 50 percent before the 1970s to nearly 80 percent today, and the 10-year survival rate is greater than 75 percent.

Despite these advances, treatments for some childhood cancers, including brain tumors and neuroblastoma, are inadequate. Two-thirds of children who are successfully treated experience serious and long-term effects from treatment. Negative effects resulting from current pediatric cancer therapies indicate a need to strengthen Federal support for activities leading to an enhanced understanding of childhood cancers and treatments that are less toxic and more effective.

H.R. 1553 would strengthen Federal investment in pediatric cancer research by advancing medical research and treatments into pediatric cancers, ensuring patients and families have access to current treatments and information regarding pediatric cancers, and promoting public awareness of pediatric cancers.

#### HEARINGS

No hearings were held in connection with H.R. 1553.

#### COMMITTEE CONSIDERATION

On Wednesday, April 23, 2008, the Subcommittee on Health met in open markup session and favorably forwarded H.R. 1553, amended, to the full Committee for consideration by a voice vote. On Wednesday, May 7, 2008, the full Committee met in open markup session and ordered H.R. 1553 favorably reported to the House, amended, by a voice vote.

#### COMMITTEE VOTES

Clause 3(b) of rule XIII of the Rules of the House of Representatives requires the Committee to list the record votes on the motion to report legislation and amendments thereto. No record votes were taken on amendments or in connection with ordering H.R. 1553 reported to the House. A motion by Mr. Dingell to order H.R. 1553 favorably reported to the House, amended, was agreed to by a voice vote.

#### COMMITTEE OVERSIGHT FINDINGS

Regarding clause 3(c)(1) of rule XIII of the Rules of the House of Representatives, the oversight findings of the Committee regarding H.R. 1553 are reflected in this report.

## STATEMENT OF GENERAL PERFORMANCE GOALS AND OBJECTIVES

The objective of H.R. 1553 is to amend the Public Health Service Act to encourage the Secretary of the Department of Health and Human Services (HHS), in collaboration with the Director of the National Institutes of Health (NIH) and other Federal agencies to continue to enhance, expand, and intensify pediatric cancer research and other activities related to pediatric cancer. In doing so, the Secretary of HHS is encouraged to take into consideration the application of such research and other activities for minority, health disparity, and medically underserved communities.

## NEW BUDGET AUTHORITY, ENTITLEMENT AUTHORITY, AND TAX EXPENDITURES

Regarding compliance with clause 3(c)(2) of rule XIII of the Rules of the House of Representatives, the Committee finds that H.R. 1553 would result in no new or increased budget authority, entitlement authority, or tax expenditures or revenues.

## EARMARKS AND TAX AND TARIFF BENEFITS

Regarding compliance with clause 9 of rule XXI of the Rules of the House of Representatives, H.R. 1553 does not contain any congressional earmarks, limited tax benefits, or limited tariff benefits as defined in clause 9(d), 9(e), or 9(f) of rule XXI.

## COMMITTEE COST ESTIMATE

The Committee adopts as its own the cost estimate on H.R. 1553 prepared by the Director of the Congressional Budget Office pursuant to section 402 of the Congressional Budget Act of 1974.

## CONGRESSIONAL BUDGET OFFICE ESTIMATE

Pursuant to clause 3(c)(3) of rule XIII of the Rules of the House of Representatives, the following is the cost estimate on H.R. 1553 provided by the Congressional Budget Office pursuant to section 402 of the Congressional Budget Act of 1974:

U.S. CONGRESS,  
CONGRESSIONAL BUDGET OFFICE,  
*Washington, DC, May 20, 2008.*

Hon. JOHN D. DINGELL,  
*Chairman, Committee on Energy and Commerce,  
House of Representatives, Washington, DC.*

DEAR MR. CHAIRMAN: The Congressional Budget Office has prepared the enclosed cost estimate for H.R. 1553, the Caroline Pryce Walker Conquer Childhood Cancer Act of 2008.

If you wish further details on this estimate, we will be pleased to provide them. The CBO staff contact is Sarah Evans.

Sincerely,

PETER R. ORSZAG.

Enclosure.

*H.R. 1553—Caroline Pryce Walker Conquer Childhood Cancer Act of 2008*

Summary: H.R. 1553 would amend the Public Health Service (PHS) Act to instruct the Director of the National Institutes of Health (NIH) to enhance, expand, and intensify research to generate effective treatments for pediatric cancer. The bill would authorize the Secretary of Health and Human Services (HHS) to award grants to professional and direct-service organizations to increase public awareness of treatments and support networks available for pediatric cancer patients and their families. H.R. 1553 also would require the Director of the Centers for Disease Control and Prevention (CDC) to create a registry to enhance epidemiological research on pediatric cancer.

H.R. 1553 would authorize the appropriation of \$30 million a year for fiscal years 2009 through 2013. CBO estimates that implementing the bill would cost \$119 million over the 2009–2013 period, assuming the appropriation of the specified amounts. Enacting H.R. 1553 would have no effect on direct spending or revenues.

The bill contains no private-sector or intergovernmental mandates as defined in the Unfunded Mandates Reform Act (UMRA) and would impose no costs on state, local, or tribal governments.

Estimated cost to the Federal Government: The estimated budgetary impact of H.R. 1553 is shown in the following table. The costs of this legislation fall within budget function 550 (health).

	By fiscal year, in millions of dollars—					
	2009	2010	2011	2012	2013	2009–2013
CHANGES IN SPENDING SUBJECT TO APPROPRIATION						
Authorization Level .....	30	30	30	30	30	150
Estimated Outlays .....	9	24	28	29	29	119

Basis of estimate: H.R. 1553 would authorize the appropriation of \$30 million for each of fiscal years 2009 through 2013. For this estimate, CBO assumes that H.R. 1553 will be enacted near the start of fiscal year 2009 and that the authorized amounts will be appropriated for each year. Using historical patterns of spending for similar programs, CBO estimates that implementing H.R. 1553 would cost \$119 million over the 2009–2013 period.

H.R. 1553 would instruct the Secretary of HHS, acting through the Director of NIH, to collaborate with other federal agencies to enhance, expand, and intensify their research to generate effective treatments for pediatric cancers. The Secretary would be authorized to award grants to professional and direct-service organizations to expand activities that increase awareness of treatments, long-term effects of pediatric cancer, and support networks for patients and parents. H.R. 1553 also would direct the Secretary of HHS, acting through the Director of the CDC, to award a grant to create a national registry of cases of pediatric cancer that could be used for epidemiological studies.

The National Cancer Institute (NCI), which supports the majority of pediatric cancer activities at the NIH, spent \$173 million on childhood cancer activities in fiscal year 2007. Over the past few years, childhood cancer activities at NCI have included: research on the causes, diagnosis, treatment, and prevention of childhood can-

cers; a national campaign to increase understanding of childhood cancer; and a study of the feasibility of establishing a Childhood Cancer Research Network to develop a national registry of childhood cancers.

**Intergovernmental and private-sector impact:** H.R. 1553 contains no private-sector intergovernmental mandates as defined in UMRA and would impose no costs on state, local, or tribal governments.

**Previous estimate:** On December 19, 2007, CBO transmitted an estimate for S. 911, the Conquer Childhood Cancer Act of 2007, as reported by the Senate Committee on Health, Education, Labor, and Pensions on December 12, 2007. H.R. 1553 is very similar to S. 911. The major difference between the bills is that H.R. 1553 would require an increased focus on health disparity issues that was not explicitly required in S. 911. CBO does not estimate any impact on costs from this change. The slight change in CBO's estimate for H.R. 1553 reflects updated historical information on spending for cancer research and outreach activities at NIH.

**Estimate prepared by:** Federal costs: Sarah Evans and Tim Gronniger; Impact on state, local and tribal governments: Lisa Ramirez-Branum; Impact on the private sector: Patrick Bernhardt.

**Estimate approved by:** Keith J. Fontenot, Deputy Assistant Director for Health and Human Resources, Budget Analysis Division.

#### FEDERAL MANDATES STATEMENT

The Committee adopts as its own the estimate of Federal mandates regarding H.R. 1553 prepared by the Director of the Congressional Budget Office pursuant to section 423 of the Unfunded Mandates Reform Act.

#### ADVISORY COMMITTEE STATEMENT

No advisory committees within the meaning of section 5(b) of the Federal Advisory Committee Act would be created by H.R. 1553.

#### CONSTITUTIONAL AUTHORITY STATEMENT

Pursuant to clause 3(d)(1) of rule XIII of the Rules of the House of Representatives, the Committee finds that the Constitutional authority for H.R. 1553 is provided in the provisions of Article I, section 8, clause 1, that relate to expending funds to provide for the general welfare of the United States.

#### APPLICABILITY TO LEGISLATIVE BRANCH

The Committee finds that H.R. 1553 does not relate to the terms and conditions of employment or access to public services or accommodations within the meaning of section 102(b)(3) of the Congressional Accountability Act of 1995.

#### SECTION-BY-SECTION ANALYSIS OF THE LEGISLATION

##### *Section 1. Short title*

Section 1 establishes the short title of the Act as the "Caroline Pryce Walker Conquer Childhood Cancer Act of 2008".

##### *Section 2. Findings*

Section 2 lists the findings.

*Section 3. Purposes*

Section 3 states that the purposes of the legislation include: (1) Encouraging support for pediatric cancer research and other activities related to pediatric cancer; (2) establishing a comprehensive national childhood cancer registry; and (3) providing informational services to patients and families affected by childhood cancer.

*Section 4. Pediatric cancer research and awareness; national childhood cancer registry*

Section 4 amends Subpart 1 of part C of title IV of the Public Health Service Act (42 U.S.C. 285 et seq.) by inserting a new section 417E, which states that the Secretary of HHS, in collaboration with the Director of the 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 of HHS is encouraged to take into consideration the application of such research and other activities for minority, health disparity, and medically underserved communities. All grants awarded under this section shall be awarded in accordance with section 492.

Section 4 also states that the Secretary of HHS may award grants to childhood cancer professional and direct service organizations for the expansion and widespread implementation of: (1) Activities that provide available information on treatment protocols to ensure early access to the best available therapies and clinical trials for pediatric cancers; (2) 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 (3) 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 these grants, the Secretary of HHS is encouraged to take into consideration the extent to which an entity would use such grant for purposes of making activities and services available to minority, health disparity, and medically underserved communities. For each grant awarded under this subsection, the Secretary of HHS shall develop and implement metrics-based performance measures to assess the effectiveness of activities funded under such grant.

Section 4 states that any information made available pursuant to a grant awarded in this section shall be approved by the Secretary of HHS and must be culturally and linguistically appropriate as needed by patients and families affected by childhood cancer.

Section 4 states that 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).

For purposes of carrying out section 4 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 under section 402A with respect to such purposes. Funds appropriated under this subsection shall remain available until expended.

Section 4 amends Part M of title III of the Public Health Service Act (42 U.S.C. 280e et seq.) by inserting a new section 399E–1, which states that the Secretary of HHS, acting through the Director of the CDC, 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. This registry 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.

CHANGES IN EXISTING LAW MADE BY THE BILL, AS REPORTED

In compliance with clause 3(e) of rule XIII of the Rules of the House of Representatives, changes in existing law made by the bill, as reported, are shown as follows (new matter is printed in italic and existing law in which no change is proposed is shown in roman):

**PUBLIC HEALTH SERVICE ACT**

\* \* \* \* \*

**TITLE III—GENERAL POWERS AND DUTIES OF PUBLIC HEALTH SERVICE**

\* \* \* \* \*

**PART M—NATIONAL PROGRAM OF CANCER REGISTRIES**

\* \* \* \* \*

**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.*

**SEC. 399F. AUTHORIZATION OF APPROPRIATIONS.**

(a) REGISTRIES.—For the purpose of carrying out this part (*other than section 399E-1*), there are authorized to be appropriated \$30,000,000 for fiscal year 1994, and such sums as may be necessary for each of the fiscal years 1995 through 2003. Of the amounts appropriated under the preceding sentence for any such fiscal year, the Secretary may obligate not more than 25 percent for carrying out section 399C, and not more than 10 percent may be expended for assessing the accuracy, completeness and quality of data collected, and not more than 10 percent of which is to be expended under section 399D.

\* \* \* \* \*

**TITLE IV—NATIONAL RESEARCH INSTITUTES**

\* \* \* \* \*

**PART C—SPECIFIC PROVISIONS RESPECTING NATIONAL RESEARCH INSTITUTES**

**Subpart 1—National Cancer Institute**

\* \* \* \* \*

**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 pre-clinical 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.*

(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.*

\* \* \* \* \*

