

1 search strides made, most of those children die. Up
2 to 75 percent of the children with cancer can now
3 be cured.

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

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

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

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

19 **SEC. 3. PURPOSES.**

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

22 (1) encourage the support for pediatric cancer
23 research and other activities related to pediatric can-
24 cer;

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

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

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

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

11 **“SEC. 417E. PEDIATRIC CANCER RESEARCH AND AWARE-**
12 **NESS.**

13 “(a) PEDIATRIC CANCER RESEARCH.—

14 “(1) PROGRAMS OF RESEARCH EXCELLENCE IN
15 PEDIATRIC CANCER.—The Secretary, in collabora-
16 tion with the Director of NIH and other Federal
17 agencies with interest in prevention and treatment of
18 pediatric cancer, shall continue to enhance, expand,
19 and intensify pediatric cancer research and other ac-
20 tivities related to pediatric cancer, including thera-
21 peutically applicable research to generate effective
22 treatments, pediatric preclinical testing, and pedi-
23 atric clinical trials through National Cancer Insti-
24 tute-supported pediatric cancer clinical trial groups
25 and their member institutions. In enhancing, ex-

1 panding, and intensifying such research and other
2 activities, the Secretary is encouraged to take into
3 consideration the application of such research and
4 other activities for minority, health disparity, and
5 medically underserved communities. For purposes of
6 this section, the term ‘pediatric cancer research’
7 means research on the causes, prevention, diagnosis,
8 recognition, treatment, and long-term effects of pedi-
9 atric cancer.

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

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

15 “(1) IN GENERAL.—The Secretary may award
16 grants to childhood cancer professional and direct
17 service organizations for the expansion and wide-
18 spread implementation of—

19 “(A) activities that provide available infor-
20 mation on treatment protocols to ensure early
21 access to the best available therapies and clin-
22 ical trials for pediatric cancers;

23 “(B) activities that provide available infor-
24 mation on the late effects of pediatric cancer

1 treatment to ensure access to necessary long-
2 term medical and psychological care; and

3 “(C) direct resource services such as edu-
4 cational outreach for parents, peer-to-peer and
5 parent-to-parent support networks, information
6 on school re-entry and postsecondary education,
7 and resource directories or referral services for
8 financial assistance, psychological counseling,
9 and other support services.

10 In awarding grants under this paragraph, the Sec-
11 retary is encouraged to take into consideration the
12 extent to which an entity would use such grant for
13 purposes of making activities and services described
14 in this paragraph available to minority, health dis-
15 parity, and medically underserved communities.

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

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

1 “(A) culturally and linguistically appro-
2 priate as needed by patients and families af-
3 fected by childhood cancer; and

4 “(B) approved by the Secretary.

5 “(c) RULE OF CONSTRUCTION.—Nothing in this sec-
6 tion shall be construed as being inconsistent with the goals
7 and purposes of the Minority Health and Health Dispari-
8 ties Research and Education Act of 2000 (42 U.S.C. 202
9 note).

10 “(d) AUTHORIZATION OF APPROPRIATIONS.—For
11 purposes of carrying out this section and section 399E–
12 1, there are authorized to be appropriated \$30,000,000
13 for each of fiscal years 2009 through 2013. Such author-
14 ization of appropriations is in addition to the authoriza-
15 tion of appropriations established in section 402A with re-
16 spect to such purpose. Funds appropriated under this sub-
17 section shall remain available until expended.”.

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

21 (1) by inserting after section 399E the fol-
22 lowing:

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

24 “(a) IN GENERAL.—The Secretary, acting through
25 the Director of the Centers for Disease Control and Pre-

1 vention, shall award a grant to enhance and expand infra-
2 structure to track the epidemiology of pediatric cancer into
3 a comprehensive nationwide registry of actual occurrences
4 of pediatric cancer. Such registry shall be updated to in-
5 clude an actual occurrence within weeks of the date of
6 such occurrence.

7 “(b) INFORMED CONSENT AND PRIVACY REQUIRE-
8 MENTS AND COORDINATION WITH EXISTING PRO-
9 GRAMS.—The registry established pursuant to subsection
10 (a) shall be subject to section 552a of title 5, United
11 States Code, the regulations promulgated under section
12 264(e) of the Health Insurance Portability and Account-
13 ability Act of 1996, applicable Federal and State informed
14 consent regulations, any other applicable Federal and
15 State laws relating to the privacy of patient information,
16 and section 399B(d)(4) of this Act.”; and

17 (2) in section 399F(a), by inserting “(other
18 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 cancers”.

