109TH CONGRESS 2D SESSION

H. R. 4927

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 HOUSE OF REPRESENTATIVES

March 9, 2006

Ms. PRYCE of Ohio (for herself, Mr. McCaul of Texas, and Mr. Cannon) introduced the following bill; which was referred to the Committee on Energy and Commerce

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 treatments 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,

1 SECTION 1. SHORT TITLE.

- This Act may be cited as the "Conquer Childhood
- 3 Cancer Act of 2006".
- 4 SEC. 2. FINDINGS.
- 5 Congress makes the following findings:
- 6 (1) Cancer kills more children than any other 7 disease.
- 8 (2) Each year cancer kills more children be-9 tween 1 and 20 years of age than asthma, diabetes, 10 cystic fibrosis, and AIDS, combined.
- 11 (3) Every year, over 12,500 young people are diagnosed with cancer.
- 13 (4) Each year about 2,300 children and teen-14 agers die from cancer.
- (5) One in every 330 Americans develops cancerbefore 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) Brain tumors are now the most common cause of cancer-related death in children and are the most common solid tumor of childhood. Neuro-blastoma is the second most common pediatric solid tumor (after brain tumors) and represents a major

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- therapeutic challenge. More than 50 percent of children with metastatic disease still die despite aggressive, toxic chemotherapy regimens.
 - (8) The causes of most childhood cancers are not yet known.
 - (9) 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.
- 12 (10) Eighty percent of the children who are di-13 agnosed with cancer have disease which has already 14 spread to distant sites in the body.
 - (11) 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.

19 SEC. 3. PURPOSES.

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- 20 It is the purpose of this Act to authorize appropria-21 tions to—
- 22 (1) encourage and expand the support for bio-23 medical research programs of the existing National 24 Cancer Institute-designated multi-center national in-25 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 thereof 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 NIH, 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-
- velop a grant mechanism for the establishment, in
- cooperation with the National Cancer Institute-sup-
- ported pediatric cancer clinical trial groups, of Re-
- search Fellowships in Pediatric Cancer to support
- adequate numbers of pediatric focused clinical and
- translational investigators thereby facilitating con-
- tinuous momentum of research excellence.
- 18 "(b) National Childhood Cancer Registry.—
- 19 The Director of NIH 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 is authorized to be appropriated to carry out this section
- 9 \$20,000,000 for each of fiscal years 2007 through 2011.
- 10 Funds appropriated under this section shall remain avail-
- 11 able until expended.".

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