

**AMENDMENT IN THE NATURE OF A SUBSTITUTE
TO H.R. 1553
OFFERED BY MR. PALLONE OF NEW JERSEY**

Strike all after the enacting clause and insert the following:

1 SECTION 1. SHORT TITLE.

2 This Act may be cited as the “Conquer Childhood
3 Cancer Act of 2008”.

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
12 diagnosed with cancer.

13 (4) Each year about 2,300 children and teen-
14 agers die from cancer.

15 (5) One in every 330 Americans develops cancer
16 before age 20.

17 (6) Some forms of childhood cancer have proven
18 to be so resistant that even in spite of the great re-

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 biomedical re-
23 search programs of the existing National Cancer In-
24 stitute-designated multi-center national infrastruc-
25 ture 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; and

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.

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

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

19 **“SEC. 417E. PEDIATRIC CANCER RESEARCH AND AWARE-**
20 **NESS.**

21 “(a) PEDIATRIC CANCER RESEARCH.—

22 “(1) PROGRAMS OF RESEARCH EXCELLENCE IN
23 PEDIATRIC CANCER.—The Secretary, in collabora-
24 tion with the Director of NIH and other Federal
25 agencies with interest in prevention and treatment of

1 pediatric cancer, shall continue to enhance, expand,
2 and intensify pediatric cancer research and other ac-
3 tivities related to pediatric cancer, including thera-
4apeutically applicable research to generate effective
5 treatments, pediatric preclinical testing, and pedi-
6atric clinical trials through National Cancer Insti-
7tute-supported pediatric cancer clinical trial groups
8 and their member institutions. For purposes of this
9 section, the term ‘pediatric cancer research’ means
10 research on the causes, prevention, diagnosis, rec-
11ognition, treatment, and long-term effects of pedi-
12atric cancer.

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

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

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

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

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

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

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

18 “(c) AUTHORIZATION OF APPROPRIATIONS.—For
19 purposes of carrying out this section and section 399E–
20 1, there are authorized to be appropriated \$30,000,000
21 for each of fiscal years 2009 through 2013. Such author-
22 ization of appropriations is in addition to the authoriza-
23 tion of appropriations established in section 402A with re-
24 spect to such purpose. Funds appropriated under this sub-
25 section shall remain available until expended.”.

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

4 (1) by inserting after section 399E the fol-
5 lowing:

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

7 “(a) IN GENERAL.—The Secretary, acting through
8 the Director of the Centers for Disease Control and Pre-
9 vention, shall award a grant to enhance and expand infra-
10 structure to track the epidemiology of pediatric cancer into
11 a comprehensive nationwide registry of actual occurrences
12 of pediatric cancer. Such registry shall be updated to in-
13 clude an actual occurrence within weeks of the date of
14 such occurrence.

15 “(b) INFORMED CONSENT AND PRIVACY REQUIRE-
16 MENTS AND COORDINATION WITH EXISTING PRO-
17 GRAMS.—The registry established pursuant to subsection
18 (a) shall be subject to section 552a of title 5, United
19 States Code, the regulations promulgated under section
20 264(e) of the Health Insurance Portability and Account-
21 ability Act of 1996, applicable Federal and State informed
22 consent regulations, any other applicable Federal and
23 State laws relating to the privacy of patient information,
24 and section 399B(d)(4) of this Act.”; and

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

