

111TH CONGRESS
1ST SESSION

H. R. 653

To amend title IV of the Public Health Service Act to create a National Childhood Brain Tumor Prevention Network to provide grants and coordinate research with respect to the causes of and risk factors associated with childhood brain tumors, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

JANUARY 22, 2009

Ms. LEE of California introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To amend title IV of the Public Health Service Act to create a National Childhood Brain Tumor Prevention Network to provide grants and coordinate research with respect to the causes of and risk factors associated with childhood brain tumors, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “National Childhood
5 Brain Tumor Prevention Network Act of 2009”.

6 **SEC. 2. FINDINGS.**

7 Congress finds the following:

1 (1) Tumors kill more children than any other
2 disease and brain tumors are the second most com-
3 mon type of cancer in children.

4 (2) Childhood brain tumors are the leading
5 cause of death from solid tumors in children.

6 (3) There are newly recognized types of brain
7 tumors, as defined by the World Health Organiza-
8 tion, and many of these newly recognized types
9 occur in children.

10 (4) The causes of the overwhelming majority of
11 childhood brain tumors are unknown.

12 (5) Brain tumors have substantial costs for af-
13 fected children, the families of such children, and so-
14 ciety.

15 (6) Childhood brain tumors cause significant
16 morbidity and the loss of many years of potential
17 life.

18 (7) The prognosis for most childhood brain tu-
19 mors is dismal and survivors face lasting adverse
20 health effects.

21 (8) Because of the relatively low overall inci-
22 dence of childhood brain tumors, such tumors fre-
23 quently do not receive sufficient attention and re-
24 search funding.

1 (9) No single institution has a sufficient num-
2 ber of patients to independently conduct research
3 that will adequately address the causes of childhood
4 brain tumors.

5 (10) There has been no comprehensive study
6 analyzing all relevant clinical, biological, and epide-
7 miological aspects of childhood brain tumors to iden-
8 tify potential risk factors and determine the cause of
9 such tumors.

10 (11) Existing national cooperative clinical on-
11 cology groups primarily investigate treatment op-
12 tions and prognosis and do not typically examine the
13 origins of childhood brain tumors or the risk factors
14 associated with such tumors. A significant majority
15 of children with brain tumors are first treated by
16 neurosurgeons and not by oncologists typically in-
17 volved in such groups.

18 **SEC. 3. SENSE OF CONGRESS.**

19 It is the sense of Congress that—

20 (1) there is a need to establish a multi-center
21 research effort based on collaboration between re-
22 gional consortia in order to comprehensively study
23 the causes of childhood brain tumors and identify
24 potential risk factors;

1 (2) there is a need to encourage a collaborative
 2 effort among surgical and medical centers with epi-
 3 demiological study groups to gather comprehensive
 4 and detailed information for each child enrolled in
 5 those groups, in order to investigate environmental,
 6 nutritional, genetic, and developmental factors with
 7 respect to, and the pathological and epidemiological
 8 characteristics of, childhood brain tumors; and

9 (3) there is a need to authorize the Director of
 10 the National Institutes of Health to coordinate na-
 11 tional research efforts of governmental and non-
 12 governmental entities with respect to childhood brain
 13 tumors.

14 **SEC. 4. ESTABLISHMENT OF THE NATIONAL CHILDHOOD**
 15 **BRAIN TUMOR PREVENTION NETWORK.**

16 (a) IN GENERAL.—Subpart 1 of part C of title IV
 17 of the Public Health Service Act (42 U.S.C. 285 et seq.)
 18 is amended by adding at the end the following:

19 **“SEC. 417G. NATIONAL CHILDHOOD BRAIN TUMOR PREVEN-**
 20 **TION NETWORK.**

21 “(a) ESTABLISHMENT OF THE NATIONAL CHILD-
 22 HOOD BRAIN TUMOR PREVENTION NETWORK.—

23 “(1) IN GENERAL.—Not later than one year
 24 after the date of the enactment of this section, the
 25 Director of NIH, acting through the Director of the

1 National Cancer Institute, shall establish, admin-
2 ister, and coordinate a National Childhood Brain
3 Tumor Prevention Network (hereinafter referred to
4 in this section as the ‘Network’) for the purposes de-
5 scribed in paragraph (2).

6 “(2) PURPOSES.—The purposes of the Network
7 shall be the following:

8 “(A) Providing grants of not fewer than
9 five years duration to eligible consortia for the
10 purpose of conducting research with respect to
11 the causes of and risk factors associated with
12 childhood brain tumors.

13 “(B) Assembling a panel of experts, in-
14 cluding members of the Brain Tumor Epidemi-
15 ology Consortium and survivors of brain tu-
16 mors, to provide ongoing guidance and rec-
17 ommendations for, with respect to research
18 funded by the Network, the development of the
19 following:

20 “(i) A common study design.

21 “(ii) Standard protocols, methods,
22 procedures, and assays for collecting from
23 individuals enrolled as study participants,
24 and the parents of such individuals, a min-
25 imum data set that includes the following:

1 “(I) Environmental exposure
2 data.

3 “(II) Nutritional data.

4 “(III) Biospecimens, including
5 genomic data.

6 “(IV) Histopathological and mo-
7 lecular pathological data and speci-
8 mens.

9 “(V) Clinical and radiological
10 data.

11 “(iii) Specific analytical methods for
12 examining data.

13 “(iv) Provisions for consensus review
14 of enrolled cases.

15 “(v) An integrated data collection net-
16 work.

17 “(C) Designating a central laboratory to
18 collect, analyze, and aggregate data with re-
19 spect to research funded by the Network and to
20 make such data and analysis available to re-
21 searchers.

22 “(3) ELIGIBLE CONSORTIA.—To be eligible for
23 a grant under this section, a consortium shall dem-
24 onstrate the following:

1 “(A) The capability to annually enroll as
2 research participants a minimum of 100 indi-
3 viduals with a newly diagnosed childhood brain
4 tumor from the designated catchment area of
5 such consortium.

6 “(B) The capability to form a control
7 group by enrolling as research participants, for
8 each enrolled individual with a childhood brain
9 tumor, at least two individuals without a child-
10 hood brain tumor, who are matched demo-
11 graphically to such enrolled individual with a
12 childhood brain tumor.

13 “(C) That the designated catchment area
14 of such consortium does not overlap with the
15 designated catchment area of a consortium al-
16 ready receiving a grant under this section.

17 “(4) REPORT.—Not later than one year after
18 the date of the enactment of this section and annu-
19 ally thereafter, the Director of NIH shall submit to
20 Congress a report with respect to the Network, to be
21 made publicly available, including a summary of re-
22 search funded by the Network and a list of consortia
23 receiving grants under the Network. At the discre-
24 tion of the Director of NIH, such report may be
25 combined with other similar or existing reports.

1 “(5) AUTHORIZATION OF APPROPRIATIONS.—

2 “(A) IN GENERAL.—There is authorized to
3 be appropriated \$25,000,000 for each of fiscal
4 years 2010 through 2014, to remain available
5 until expended, to carry out this section.

6 “(B) SENSE OF CONGRESS.—It is the
7 sense of Congress that funds appropriated to
8 carry out this section should be in addition to
9 the funds already appropriated to carry out the
10 functions of the National Institutes of Health.

11 “(b) DEFINITIONS.—For purposes of this section, the
12 following definitions apply:

13 “(1) BRAIN TUMOR EPIDEMIOLOGY CONSOR-
14 TIUM.—The term ‘Brain Tumor Epidemiology Con-
15 sortium’ means the organization with such name
16 formed in 2003 after an initial meeting sponsored by
17 the National Cancer Institute’s Division of Cancer
18 Epidemiology and Genetics.

19 “(2) CATCHMENT AREA.—The term ‘catchment
20 area’ means a defined area for which population
21 data are available.

22 “(3) CHILDHOOD BRAIN TUMOR.—The term
23 ‘childhood brain tumor’ means an intracranial or
24 spinal cord tumor occurring in an individual under
25 20 years of age.

1 “(4) CONSORTIUM.—The term ‘consortium’
2 means a partnership of two or more universities,
3 health care organizations, or government agencies,
4 or any combination of such entities, serving a des-
5 ignated catchment area.”.

6 (b) TECHNICAL CORRECTION.—

7 (1) IN GENERAL.—Section 3 of the
8 Hematological Cancer Research Investment and
9 Education Act of 2002 (Public Law 107–172; 116
10 Stat. 541) is amended by striking “419C” and in-
11 serting “417C”.

12 (2) EFFECTIVE DATE.—The amendment made
13 by paragraph (1) shall take effect as if included in
14 the enactment of the Act referred to in such para-
15 graph.

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