

112TH CONGRESS  
1ST SESSION

# H. R. 1970

To amend 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.

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## IN THE HOUSE OF REPRESENTATIVES

MAY 24, 2011

Ms. LEE of California (for herself and Mr. BISHOP of Utah) introduced the following bill; which was referred to the Committee on Energy and Commerce

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## A BILL

To amend 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”.

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 and coordinate  
21               a multi-center research effort based on collaboration  
22               between regional consortia and governmental and  
23               nongovernmental entities in order to comprehen-  
24               sively study the causes of childhood brain tumors  
25               and identify potential risk factors; and

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.

9 **SEC. 4. ESTABLISHMENT OF THE NATIONAL CHILDHOOD**  
10 **BRAIN TUMOR PREVENTION NETWORK.**

11 Title III of the Public Health Service Act is amended  
12 by inserting after section 317T of such Act (42 U.S.C.  
13 247b-22) the following:

14 **“SEC. 317U. NATIONAL CHILDHOOD BRAIN TUMOR PREVEN-**  
15 **TION NETWORK.**

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

18 “(1) IN GENERAL.—Not later than one year  
19 after the date of the enactment of this section, the  
20 Secretary, acting through the Director of the Cen-  
21 ters for Disease Control and Prevention, shall estab-  
22 lish, administer, and coordinate within the National  
23 Center for Environmental Health a National Child-  
24 hood Brain Tumor Prevention Network (hereinafter

1 referred to in this section as the ‘Network’) for the  
2 purposes described in paragraph (2).

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

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

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

17 “(i) A common study design.

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

23 “(I) Environmental exposure  
24 data.

25 “(II) Nutritional data.

1                   “(III) Biospecimens, including  
2                   genomic data.

3                   “(IV) Histopathological and mo-  
4                   lecular pathological data and speci-  
5                   mens.

6                   “(V) Clinical and radiological  
7                   data.

8                   “(iii) Specific analytical methods for  
9                   examining data.

10                  “(iv) Provisions for consensus review  
11                  of enrolled cases.

12                  “(v) An integrated data collection net-  
13                  work.

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

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

22                         “(A) The capability to annually enroll as  
23                         research participants a minimum of 100 indi-  
24                         viduals with a newly diagnosed childhood brain

1 tumor from the designated catchment area of  
2 such consortium.

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

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

14 “(4) REPORT.—Not later than one year after  
15 the date of the enactment of this section and annu-  
16 ally thereafter, the Secretary, acting through the Di-  
17 rector of the Centers for Disease Control and Pre-  
18 vention, shall submit to Congress a report with re-  
19 spect to the Network, to be made publicly available,  
20 including a summary of research funded by the Net-  
21 work and a list of consortia receiving grants under  
22 the Network. At the discretion of the Secretary,  
23 such report may be combined with other similar or  
24 existing reports.

25 “(5) AUTHORIZATION OF APPROPRIATIONS.—

1           “(A) IN GENERAL.—There is authorized to  
2           be appropriated \$25,000,000 for each of fiscal  
3           years 2012 through 2016, to remain available  
4           until expended, to carry out this section.

5           “(B) SENSE OF CONGRESS.—It is the  
6           sense of Congress that funds appropriated to  
7           carry out this section should be in addition to  
8           funds otherwise available or appropriated to  
9           carry out the activities described in this section.

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

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

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

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

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