111TH CONGRESS
1ST SESSION

S. 305

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 SENATE OF THE UNITED STATES

JANUARY 22, 2009

Mr. SCHUMER (for himself and Mr. VITTER) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

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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.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the ''National Childhood Brain Tumor Prevention Network Act of 2009''.

SEC. 2. FINDINGS.

Congress finds the following:

(1) Tumors kill more children than any other disease and brain tumors are the second most common type of cancer in children.

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

(3) There are newly recognized types of brain tumors, as defined by the World Health Organization, and many of these newly recognized types occur in children.

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

(5) Brain tumors have substantial costs for affected children, the families of such children, and society.

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

(7) The prognosis for most childhood brain tumors is dismal and survivors face lasting adverse health effects.

(8) Because of the relatively low overall incidence of childhood brain tumors, such tumors frequently do not receive sufficient attention and research funding.

(9) No single institution has a sufficient number of patients to independently conduct research that will adequately address the causes of childhood brain tumors.

(10) There has been no comprehensive study analyzing all relevant clinical, biological, and epidemiological aspects of childhood brain tumors to identify potential risk factors and determine the cause of such tumors.

(11) Existing national cooperative clinical oncology groups primarily investigate treatment options and prognosis and do not typically examine the origins of childhood brain tumors or the risk factors associated with such tumors. A significant majority of children with brain tumors are first treated by neurosurgeons and not by oncologists typically involved in such groups.

SEC. 3. SENSE OF CONGRESS.

It is the sense of Congress that—

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

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

(3) there is a need to authorize the Director of the National Institutes of Health to coordinate national research efforts of governmental and nongovernmental entities with respect to childhood brain tumors.

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

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

"SEC. 417G. NATIONAL CHILDHOOD BRAIN TUMOR PREVENTION NETWORK.

''(a) ESTABLISHMENT OF THE NATIONAL CHILDHOOD BRAIN TUMOR PREVENTION NETWORK.—

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

National Cancer Institute, shall establish, administer, and coordinate a National Childhood Brain Tumor Prevention Network (hereinafter referred to in this section as the 'Network') for the purposes described in paragraph (2).

''(2) PURPOSES.—The purposes of the Network shall be the following:

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

''(B) Assembling a panel of experts, including members of the Brain Tumor Epidemiology Consortium and survivors of brain tumors, to provide ongoing guidance and recommendations for, with respect to research funded by the Network, the development of the following:

''(i) A common study design.

''(ii) Standard protocols, methods, procedures, and assays for collecting from individuals enrolled as study participants, and the parents of such individuals, a minimum data set that includes the following:

''(I) Environmental exposure data.

''(II) Nutritional data.

''(III) Biospecimens, including genomic data.

''(IV) Histopathological and molecular pathological data and specimens.

''(V) Clinical and radiological data.

''(iii) Specific analytical methods for examining data.

''(iv) Provisions for consensus review of enrolled cases.

''(v) An integrated data collection network.

''(C) Designating a central laboratory to collect, analyze, and aggregate data with respect to research funded by the Network and to make such data and analysis available to researchers.

''(3) ELIGIBLE CONSORTIA.—To be eligible for a grant under this section, a consortium shall demonstrate the following:

"(A) The capability to annually enroll as research participants a minimum of 100 individuals with a newly diagnosed childhood brain tumor from the designated catchment area of such consortium.

"(B) The capability to form a control group by enrolling as research participants, for each enrolled individual with a childhood brain tumor, at least two individuals without a childhood brain tumor, who are matched demographically to such enrolled individual with a childhood brain tumor.

"(C) That the designated catchment area of such consortium does not overlap with the designated catchment area of a consortium already receiving a grant under this section.

"(4) REPORT.—Not later than one year after the date of the enactment of this section and annually thereafter, the Director of NIH shall submit to Congress a report with respect to the Network, to be made publicly available, including a summary of research funded by the Network and a list of consortia receiving grants under the Network. At the discretion of the Director of NIH, such report may be combined with other similar or existing reports.

''(5) AUTHORIZATION OF APPROPRIATIONS.—

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

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

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

''(1) BRAIN TUMOR EPIDEMIOLOGY CONSORTIUM.—The term 'Brain Tumor Epidemiology Consortium' means the organization with such name formed in 2003 after an initial meeting sponsored by the National Cancer Institute's Division of Cancer Epidemiology and Genetics.

''(2) CATCHMENT AREA.—The term 'catchment area' means a defined area for which population data are available.

''(3) CHILDHOOD BRAIN TUMOR.—The term 'childhood brain tumor' means an intracranial or spinal cord tumor occurring in an individual under 20 years of age.

"(4) CONSORTIUM.—The term 'consortium' means a partnership of two or more universities, health care organizations, or government agencies, or any combination of such entities, serving a designated catchment area.".

(b) TECHNICAL CORRECTION.—

(1) IN GENERAL.—Section 3 of the Hematological Cancer Research Investment and Education Act of 2002 (Public Law 107–172; 116 Stat. 541) is amended by striking "419C" and inserting "417C".

(2) EFFECTIVE DATE.—The amendment made by paragraph (1) shall take effect as if included in the enactment of the Act referred to in such paragraph.

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