

counties in State of New York and northeastern United States that had highest age-adjusted mortality rate of such cancer, and to report results of such study to Congress not later than 30 months after June 10, 1993.

§ 280e-3a. National childhood cancer registry

(a) In general

The Secretary, acting through the Director of the Centers for Disease Control and Prevention, may make awards to State cancer registries to enhance and expand infrastructure to collect information to better understand the epidemiology of cancer in children, adolescents, and young adults. Such registries may be updated to include each occurrence of such cancers within a period of time designated by the Secretary.

(b) Activities

The grants described in subsection (a) may be used for—

- (1) identifying, recruiting, and training potential sources for reporting childhood, adolescent, and young adult cancer cases;
- (2) developing practices to ensure early inclusion of childhood, adolescent, and young adult cancer cases in State cancer registries through the use of electronic reporting;
- (3) collecting and submitting deidentified data to the Centers for Disease Control and Prevention for inclusion in a national database that includes information on childhood, adolescent, and young adult cancers; and
- (4) improving State cancer registries and the database described in paragraph (3), as appropriate, including to support the early inclusion of childhood, adolescent, and young adult cancer cases.

(c) Coordination

To encourage the greatest possible efficiency and effectiveness of federally supported efforts with respect to the activities described in this section, the Secretary shall ensure the appropriate coordination of programs supported under this section with other federally supported cancer registry programs and the activities under section 285a-11(a) of this title, as appropriate.

(d) Informed consent and privacy requirements and coordination with existing programs

The activities described in this section shall be subject to section 552a of title 5, the regulations promulgated under section 264(c) of the Health Insurance Portability and Accountability Act of 1996, applicable Federal and State informed consent regulations, any other applicable Federal and State laws relating to the privacy of patient information, and section 280e(d)(4) of this title.

(July 1, 1944, ch. 373, title III, § 399E-1, as added Pub. L. 110-285, § 4(b)(1), July 29, 2008, 122 Stat. 2630; amended Pub. L. 115-180, title I, § 102(a), June 5, 2018, 132 Stat. 1385.)

REFERENCES IN TEXT

Section 264(c) of the Health Insurance Portability and Accountability Act of 1996, referred to in subsec. (d), is section 264(c) of Pub. L. 104-191, which is set out as a note under section 1320d-2 of this title.

AMENDMENTS

2018—Subsec. (a). Pub. L. 115-180, § 102(a)(1), substituted “may make awards to State cancer registries”

for “shall award a grant”, “collect information to better understand the epidemiology of cancer in children, adolescents, and young adults” for “track the epidemiology of pediatric cancer into a comprehensive nationwide registry of actual occurrences of pediatric cancer”, and “Such registries may be updated to include each occurrence of such cancers within a period of time designated by the Secretary.” for “Such registry shall be updated to include an actual occurrence within weeks of the date of such occurrence.”

Subsecs. (b), (c). Pub. L. 115-180, § 102(a)(3), added subsecs. (b) and (c). Former subsec. (b) redesignated (d).

Subsec. (d). Pub. L. 115-180, § 102(a)(2), (4), redesignated subsec. (b) as (d) and substituted “activities described in this section” for “registry established pursuant to subsection (a)”.

FINDINGS AND PURPOSES

Pub. L. 110-285, §§ 2, 3, July 29, 2008, 122 Stat. 2628, provided that:

“SEC. 2. FINDINGS

“Congress makes the following findings:

“(1) Cancer kills more children than any other disease.

“(2) Each year cancer kills more children between 1 and 20 years of age than asthma, diabetes, cystic fibrosis, and AIDS, combined.

“(3) Every year, over 12,500 young people are diagnosed with cancer.

“(4) Each year about 2,300 children and teenagers die from cancer.

“(5) One in every 330 Americans develops cancer before 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) The causes of most childhood cancers are not yet known.

“(8) 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.

“(9) Eighty percent of the children who are diagnosed with cancer have disease which has already spread to distant sites in the body.

“(10) 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.

“SEC. 3. PURPOSES

“It is the purpose of this Act [see Short Title of 2008 Amendment note set out under section 201 of this title] to authorize appropriations to—

“(1) encourage the support for pediatric cancer research and other activities related to pediatric cancer;

“(2) establish a comprehensive national childhood cancer registry; and

“(3) provide informational services to patients and families affected by childhood cancer.”

§ 280e-4. Authorization of appropriations

(a) Registries

For the purpose of carrying out this part (other than section 280e-3a of this title), there are authorized to be appropriated \$30,000,000 for fiscal year 1994, and such sums as may be necessary for each of the fiscal years 1995 through 2003. Of the amounts appropriated under the preceding sentence for any such fiscal year, the Secretary may obligate not more than 25 percent for carrying out section 280e-1 of this title,