

REPORT OF INSPECTOR GENERAL; PLAN REGARDING
RELATIONSHIP BETWEEN REGISTRY AND DONOR CENTERS

Pub. L. 105-196, §2(b)(2), July 16, 1998, 112 Stat. 632, directed the Secretary of Health and Human Services to ensure that, not later than 1 year after July 16, 1998, the National Bone Marrow Donor Registry (under this section) developed, evaluated, and implemented a plan to effectuate efficiencies in the relationship between such Registry and donor centers.

STUDY BY GAO

Pub. L. 105-196, §5, July 16, 1998, 112 Stat. 636, provided that the Comptroller General was to conduct a study of the National Bone Marrow Donor Registry under this section to determine the extent to which the Registry had increased the representation of racial and ethnic minority groups among potential donors enrolled with the Registry and whether the extent of increase resulted in a level of representation that met the standard established in subsec. (c)(1)(A) of this section, the extent to which patients in need of a transplant of bone marrow from a biologically unrelated donor, and the physicians of such patients, had been utilizing the Registry, the number of patients for whom the Registry began a preliminary but not complete search process and the reasons underlying such circumstances, the extent to which the plan required in section 2(b)(2) of Pub. L. 105-196 (42 U.S.C. 274k note) had been implemented, and the extent to which the Registry, donor centers, donor registries, collection centers, transplant centers, and other appropriate entities had been complying with subsec. (e) of this section; and provided that a report describing the findings of this study was to be submitted to Congress not later than Oct. 1, 2001, and not before Jan. 1, 2001.

COMPLIANCE WITH NEW REQUIREMENTS FOR OFFICE OF
PATIENT ADVOCACY

Pub. L. 105-196, §6, July 16, 1998, 112 Stat. 636, provided that with respect to requirements for the office of patient advocacy under subsec. (d) of this section, the Secretary of Health and Human Services was to ensure that, not later than 180 days after Oct. 1, 1998, such office was in compliance with all requirements that were additional to the requirements under this section in effect with respect to patient advocacy on the day before July 16, 1998.

§ 274l. Stem cell therapeutic outcomes database

(a) Establishment

The Secretary shall by contract establish and maintain a scientific database of information relating to patients who have been recipients of a stem cell therapeutics product (including bone marrow, cord blood, or other such product) from a donor.

(b) Information

The outcomes database shall include information in a standardized electronic format with respect to patients described in subsection (a), diagnosis, transplant procedures, results, long-term follow-up, and such other information as the Secretary determines to be appropriate, to conduct an ongoing evaluation of the scientific and clinical status of transplantation involving recipients of a stem cell therapeutics product from a donor.

(c) Annual report on patient outcomes

The Secretary shall require the entity awarded a contract under this section to submit to the Secretary an annual report concerning patient outcomes with respect to each transplant center, based on data collected and maintained by the entity pursuant to this section.

(d) Publicly available data

The outcomes database shall make relevant scientific information not containing individually identifiable information available to the public in the form of summaries and data sets to encourage medical research and to provide information to transplant programs, physicians, patients, entities awarded a contract under section 274k of this title¹ donor registries, and cord blood banks.

(July 1, 1944, ch. 373, title III, §379A, as added Pub. L. 105-196, §3, July 16, 1998, 112 Stat. 635; amended Pub. L. 109-129, §3(b), Dec. 20, 2005, 119 Stat. 2561.)

Editorial Notes

PRIOR PROVISIONS

A prior section 274l, act July 1, 1944, ch. 373, title III, §379A, as added Pub. L. 101-616, title I, §101(a)(2), Nov. 16, 1990, 104 Stat. 3282, related to study by General Accounting Office, prior to repeal by Pub. L. 105-196, §§3, 7, July 16, 1998, 112 Stat. 635, 637, effective Oct. 1, 1998.

AMENDMENTS

2005—Pub. L. 109-129, amended section generally, substituting provisions relating to the stem cell therapeutic outcomes database for provisions relating to the bone marrow scientific registry.

Statutory Notes and Related Subsidiaries

EFFECTIVE DATE

Section effective Oct. 1, 1998, see section 7 of Pub. L. 105-196, set out as an Effective Date of 1998 Amendment note under section 274k of this title.

§ 274l-1. Definitions

In this part:

(1) The term “Advisory Council” means the advisory council established by the Secretary under section 274k(a)(1) of this title.

(2) The term “bone marrow” means the cells found in adult bone marrow and peripheral blood.

(3) The term “outcomes database” means the database established by the Secretary under section 274l of this title.

(4) The term “Program” means the C.W. Bill Young Cell Transplantation Program established under section 274k of this title.

(July 1, 1944, ch. 373, title III, §379A-1, as added Pub. L. 109-129, §3(c), Dec. 20, 2005, 119 Stat. 2562.)

§ 274m. Authorization of appropriations

For the purpose of carrying out this part, there are authorized to be appropriated \$31,009,000 for each of fiscal years 2022 through 2026.

(July 1, 1944, ch. 373, title III, §379B, as added Pub. L. 105-196, §4(2), July 16, 1998, 112 Stat. 636; amended Pub. L. 109-129, §3(d), Dec. 20, 2005, 119 Stat. 2562; Pub. L. 111-264, §2(d), Oct. 8, 2010, 124 Stat. 2792; Pub. L. 114-104, §2(b), Dec. 18, 2015, 129 Stat. 2216; Pub. L. 117-15, §2(d), May 26, 2021, 135 Stat. 278.)

¹ So in original. Probably should be followed by a comma.