

104TH CONGRESS
1ST SESSION

S. 184

To establish an Office for Rare Disease Research in the National Institutes of Health, and for other purposes.

IN THE SENATE OF THE UNITED STATES

JANUARY 9, 1995

Mr. HATFIELD introduced the following bill; which was read twice and referred to the Committee on Labor and Human Resources

A BILL

To establish an Office for Rare Disease Research in the National Institutes of Health, 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 “Office for Rare Disease
5 Research Act of 1995”.

6 **SEC. 2. ESTABLISHMENT OF OFFICE FOR RARE DISEASE**
7 **RESEARCH.**

8 Part A of title IV of the Public Health Service Act
9 (42 U.S.C. 281 et seq.) is amended by adding at the end
10 thereof the following new section:

1 **“SEC. 404F. OFFICE FOR RARE DISEASE RESEARCH.**

2 “(a) ESTABLISHMENT.—There is established within
3 the Office of the Director of the National Institutes of
4 Health an office to be known as the Office for Rare Dis-
5 ease Research (in this section referred to as the ‘Office’).
6 The Office shall be headed by a director, who shall be ap-
7 pointed by the Director of the National Institutes of
8 Health.

9 “(b) PURPOSE.—The purpose of the Office is to pro-
10 mote and coordinate the conduct of research on rare dis-
11 eases through a strategic research plan and to establish
12 and manage a rare disease research clinical database.

13 “(c) ADVISORY COUNCIL.—The Secretary shall es-
14 tablish an advisory council for the purpose of providing
15 advice to the director of the Office concerning carrying
16 out the strategic research plan and other duties under this
17 section. Section 222 shall apply to such council to the
18 same extent and in the same manner as such section ap-
19 plies to committees or councils established under such sec-
20 tion.

21 “(d) DUTIES.—In carrying out subsection (b), the di-
22 rector of the Office shall—

23 “(1) develop a comprehensive plan for the con-
24 duct and support of research on rare diseases;

25 “(2) coordinate and disseminate information
26 among the institutes and the public on rare diseases;

1 “(3) support research training and encourage
2 the participation of a diversity of individuals in the
3 conduct of rare disease research;

4 “(4) identify projects or research on rare dis-
5 eases that should be conducted or supported by the
6 National Institutes of Health;

7 “(5) develop and maintain a central database
8 on current government sponsored clinical research
9 projects for rare diseases;

10 “(6) determine the need for registries of re-
11 search subjects and epidemiological studies of rare
12 disease populations; and

13 “(7) prepare biennial reports on the activities
14 carried out or to be carried out by the Office and
15 submit such reports to the Secretary and the Con-
16 gress.”.

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