

COMMITTEE PRINT

[SHOWING TEXT OF H.R. 1230 AS FORWARDED BY THE SUBCOMMITTEE
ON HEALTH ON SEPTEMBER 16, 2010]

111TH CONGRESS
1ST SESSION

H. R. 1230

To amend the Public Health Service Act to provide for the establishment of a National Acquired Bone Marrow Failure Disease Registry, to authorize research on acquired bone marrow failure diseases, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 26, 2009

Ms. MATSUI (for herself, Mr. BISHOP of Georgia, Mr. MURTHA, Mr. McDERMOTT, Mrs. EMERSON, Mr. GENE GREEN of Texas, Mr. ABERCROMBIE, Ms. SCHWARTZ, Mr. CONYERS, Ms. HIRONO, Ms. BORDALLO, Mr. LEWIS of Georgia, Mr. FRANK of Massachusetts, Mr. WOLF, Mr. KING of New York, Mr. VAN HOLLEN, Mr. MCGOVERN, Ms. DEGETTE, Mr. ARCURI, and Ms. ESHOO) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To amend the Public Health Service Act to provide for the establishment of a National Acquired Bone Marrow Failure Disease Registry, to authorize research on acquired bone marrow failure diseases, 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,*

1 **SECTION 1. SHORT TITLE.**

2 This Act may be cited as the “Acquired Bone Marrow
3 Failure Disease Research and Treatment Act of 2010”.

4 **SEC. 2. ACQUIRED BONE MARROW FAILURE DISEASE RE-**
5 **SEARCH.**

6 Part B of title III of the Public Health Service Act
7 (42 U.S.C. 243 et seq.) is amended by inserting after sec-
8 tion 317T the following:

9 **“SEC. 317U. ACQUIRED BONE MARROW FAILURE DISEASE**
10 **RESEARCH.**

11 “(a) IN GENERAL.—The Secretary may conduct re-
12 search on acquired bone marrow failure diseases. Such re-
13 search may address factors including—

14 “(1) trends in the characteristics of individuals
15 who are diagnosed with acquired bone marrow fail-
16 ure diseases, including age, race and ethnicity, gen-
17 eral geographic location, sex, family history, and any
18 other characteristics determined appropriate by the
19 Secretary;

20 “(2) the genetic and environmental factors, in-
21 cluding exposure to toxins, that may be associated
22 with developing acquired bone marrow failure dis-
23 eases;

24 “(3) approaches to treating acquired bone mar-
25 row failure diseases;

1 “(4) outcomes for individuals treated for ac-
2 quired bone marrow failure diseases, including out-
3 comes for recipients of stem cell therapeutic prod-
4 ucts; and

5 “(5) any other factors pertaining to acquired
6 bone marrow failure diseases determined appropriate
7 by the Secretary.

8 “(b) COLLABORATION WITH THE RADIATION INJURY
9 TREATMENT NETWORK.—In carrying out subsection (a),
10 the Secretary may collaborate with the Radiation Injury
11 Treatment Network of the C.W. Bill Young Cell Trans-
12 plantation Program established pursuant to section 379
13 to—

14 “(1) augment data for the studies under such
15 subsection;

16 “(2) access technical assistance that may be
17 provided by the Radiation Injury Treatment Net-
18 work; or

19 “(3) perform joint research projects.

20 “(c) DEFINITION.—In this section, the term ‘ac-
21 quired bone marrow failure disease’ means—

22 “(1) myelodysplastic syndromes (MDS);

23 “(2) aplastic anemia;

24 “(3) paroxysmal nocturnal hemoglobinuria
25 (PNH);

1 “(4) pure red cell aplasia;

2 “(5) acute myeloid leukemia that has pro-
3 gressed from myelodysplastic syndromes;

4 “(6) large granular lymphocytic leukemia; or

5 “(7) any other bone marrow failure disease
6 specified by the Secretary, to the extent such disease
7 is acquired and not inherited, as determined by the
8 Secretary.”.

9 **SEC. 3. MINORITY-FOCUSED PROGRAMS ON ACQUIRED**
10 **BONE MARROW FAILURE DISEASES.**

11 Title XVII of the Public Health Service Act (42
12 U.S.C. 300u et seq.) is amended by inserting after section
13 1707A the following:

14 **“SEC. 1707B. MINORITY-FOCUSED PROGRAMS ON AC-**
15 **QUIRED BONE MARROW FAILURE DISEASES.**

16 “(a) INFORMATION AND REFERRAL SERVICES.—

17 “(1) IN GENERAL.—The Secretary may estab-
18 lish and coordinate outreach and informational pro-
19 grams targeted to minority populations, including
20 Hispanic, Asian-American, Native Hawaiian, and
21 Pacific Islander populations, that are affected by ac-
22 quired bone marrow failure diseases.

23 “(2) PROGRAM ACTIVITIES.—Programs under
24 subsection (a) may carry out activities that in-
25 clude—

1 “(A) making information about treatment
2 options and clinical trials for acquired bone
3 marrow failure diseases publicly available; and

4 “(B) providing referral services for treat-
5 ment options and clinical trials.

6 “(b) DEFINITION.—In this section, the term ‘ac-
7 quired bone marrow failure disease’ has the meaning given
8 such term in section 317U(c).”.

9 **SEC. 4. BEST PRACTICES FOR DIAGNOSIS OF AND CARE**
10 **FOR INDIVIDUALS WITH ACQUIRED BONE**
11 **MARROW FAILURE DISEASES.**

12 Part B of title III of the Public Health Service Act
13 (42 U.S.C. 243 et seq.), as amended by section 2, is fur-
14 ther amended by inserting after section 317U the fol-
15 lowing:

16 **“SEC. 317V. BEST PRACTICES FOR DIAGNOSIS OF AND CARE**
17 **FOR INDIVIDUALS WITH ACQUIRED BONE**
18 **MARROW FAILURE DISEASES.**

19 “(a) GRANTS.—The Secretary, acting through the
20 Director of the Agency for Healthcare Research and Qual-
21 ity, may award grants to researchers to study best prac-
22 tices with respect to diagnosing acquired bone marrow
23 failure diseases and providing care to individuals with such
24 diseases.

1 “(b) DEFINITION.—In this section, the term ‘ac-
2 quired bone marrow failure disease’ has the meaning given
3 such term in section 317U(c).”.

Amend the title so as to read: “A bill to amend the Public Health Service Act to provide for research on acquired bone marrow failure diseases, minority-focused programs on such diseases, and the development of best practices for diagnosis of and care for individuals with such diseases.”.