

**AMENDMENT IN THE NATURE OF A SUBSTITUTE  
TO H.R. 1230**

**OFFERED BY M<sub>r.</sub> Pallone**

Strike all after the enacting clause and insert the following:

**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

1 other characteristics determined appropriate by the  
2 Secretary;

3 “(2) the genetic and environmental factors, in-  
4 cluding exposure to toxins, that may be associated  
5 with developing acquired bone marrow failure dis-  
6 eases;

7 “(3) approaches to treating acquired bone mar-  
8 row failure diseases;

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

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

16 “(b) COLLABORATION WITH THE RADIATION INJURY  
17 TREATMENT NETWORK.—In carrying out subsection (a),  
18 the Secretary may collaborate with the Radiation Injury  
19 Treatment Network of the C.W. Bill Young Cell Trans-  
20 plantation Program established pursuant to section 379  
21 to—

22 “(1) augment data for the studies under such  
23 subsection;

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

4           “(3) perform joint research projects.

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

7           “(1) myelodysplastic syndromes (MDS);

8           “(2) aplastic anemia;

9           “(3) paroxysmal nocturnal hemoglobinuria  
10          (PNH);

11          “(4) pure red cell aplasia;

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

14          “(6) large granular lymphocytic leukemia; or

15          “(7) any other bone marrow failure disease  
16          specified by the Secretary, to the extent such disease  
17          is acquired and not inherited, as determined by the  
18          Secretary.”.

19   **SEC. 3. MINORITY-FOCUSED PROGRAMS ON ACQUIRED**  
20                   **BONE MARROW FAILURE DISEASES.**

21          Title XVII of the Public Health Service Act (42  
22   U.S.C. 300u et seq.) is amended by inserting after section  
23   1707A the following:

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

3 “(a) INFORMATION AND REFERRAL SERVICES.—

4 “(1) IN GENERAL.—The Secretary may estab-  
5 lish and coordinate outreach and informational pro-  
6 grams targeted to minority populations, including  
7 Hispanic, Asian-American, Native Hawaiian, and  
8 Pacific Islander populations, that are affected by ac-  
9 quired bone marrow failure diseases.

10 “(2) PROGRAM ACTIVITIES.—Programs under  
11 subsection (a) may carry out activities that in-  
12 clude—

13 “(A) making information about treatment  
14 options and clinical trials for acquired bone  
15 marrow failure diseases publicly available; and

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

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

21 **SEC. 4. BEST PRACTICES FOR DIAGNOSIS OF AND CARE**  
22 **FOR INDIVIDUALS WITH ACQUIRED BONE**  
23 **MARROW FAILURE DISEASES.**

24 Part B of title III of the Public Health Service Act  
25 (42 U.S.C. 243 et seq.), as amended by section 2, is fur-

1 ther amended by inserting after section 317U the fol-  
2 lowing:

3 **“SEC. 317V. BEST PRACTICES FOR DIAGNOSIS OF AND CARE**  
4 **FOR INDIVIDUALS WITH ACQUIRED BONE**  
5 **MARROW FAILURE DISEASES.**

6 “(a) GRANTS.—The Secretary, acting through the  
7 Director of the Agency for Healthcare Research and Qual-  
8 ity, may award grants to researchers to study best prac-  
9 tices with respect to diagnosing acquired bone marrow  
10 failure diseases and providing care to individuals with such  
11 diseases.

12 “(b) DEFINITION.—In this section, the term ‘ac-  
13 quired bone marrow failure disease’ has the meaning given  
14 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 ac-  
quired 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.”.

