

SIXTEENTH CONGRESS OF THE REPUBLIC )  
OF THE PHILIPPINES )  
Second Regular Session )

SECRET  
Office of the Secretary  
JAN 28 P4:18

SENATE  
S. No. 2592

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Introduced by Senator Miriam Defensor Santiago

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AN ACT  
TO ESTABLISH A NATIONAL ACQUIRED BONE MARROW FAILURE DISEASE  
REGISTRY ON ACQUIRED BONE MARROW FAILURE DISEASES

EXPLANATORY NOTE

The Constitution, Article 2, Section 15 provides: "The State shall protect and promote the right to health of the people and instill health consciousness among them.

Acquired bone marrow failure diseases reportedly have a debilitating and often fatal impact on those diagnosed with these diseases. While some treatments for acquired bone marrow failure diseases can prolong and improve the quality of patients' lives, there is no single cure for these diseases.

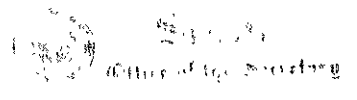
In the United States, the National Marrow Donor Program Registry has supposedly made significant contributions to the fight against bone marrow failure diseases by connecting millions of potential marrow donors with individuals and families suffering from these conditions.

Thus, this bill directs the Secretary of the Department of Health to establish a National Acquired Bone Marrow Failure Disease Registry on acquired bone marrow failure diseases.<sup>1</sup>

*Miriam Defensor Santiago*  
MIRIAM DEFENSOR SANTIAGO  
*JP*

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<sup>1</sup> This bill was originally filed by Rep. Doris Matsui in the U.S. House of Representatives during the 112<sup>th</sup> Congress, 1<sup>st</sup> Session.



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*Be it enacted by the Senate and House of Representatives of the Philippines in Congress assembled:*

1 AN ACT  
2 TO ESTABLISH A NATIONAL ACQUIRED BONE MARROW FAILURE DISEASE  
3 REGISTRY ON ACQUIRED BONE MARROW FAILURE DISEASES

4 SECTION 1. *Short Title.* – This Act shall be known as the “Bone Marrow Failure  
5 Disease Research Act.”

6 SECTION 2. *Definition of Terms.* – For purposes of this Act, the term “acquired  
7 bone marrow failure disease” means:

- 8 (1) myelodysplastic syndromes (MDS);
- 9 (2) aplastic anemia;
- 10 (3) paroxysmal nocturnal hemoglobinuria (PNH);
- 11 (4) pure red cell aplasia;
- 12 (5) acute myeloid leukemia that progressed from myelodysplastic syndromes; or
- 13 (6) large granular lymphocytic leukemia.

14 SECTION 3. *National Acquired Bone Marrow Failure Disease Registry.* –

15 (a) *Establishment of Registry* –

16 (1) *In General.* – Not later than 6 months after the date of effectivity of this  
17 Act, the Secretary of the Department of Health (here called the “Secretary”) shall:

1 (A) develop a system to collect data on acquired bone marrow  
2 failure diseases; and

3 (B) establish and maintain a national and publicly available registry,  
4 to be known as the National Acquired Bone Marrow Failure Disease  
5 Registry, in accordance with paragraph (3).

6 (2) *Recommendations of Advisory Committee.* – In carrying out this Act,  
7 the Secretary shall take into consideration the recommendations of the Advisory  
8 Committee on Acquired Bone Marrow Failure Diseases.

9 (3) *Purposes of Registry.* – The National Acquired Bone Marrow Failure  
10 Disease Registry shall:

11 (A) identify the incidence and prevalence of acquired bone marrow  
12 failure diseases in the Philippines;

13 (B) be used to collect and store data on acquired bone marrow  
14 failure diseases, including data concerning:

15 (i) the age, race or ethnicity, general geographic location, sex,  
16 and family history of individuals who are diagnosed with acquired  
17 bone marrow failure diseases, and any other characteristics of such  
18 individuals determined appropriate by the Secretary;

19 (ii) the genetic and environmental factors that may be  
20 associated with developing acquired bone marrow failure diseases;

21 (iii) treatment approaches for dealing with acquired bone  
22 marrow failure diseases;

23 (iv) outcomes for individuals treated for acquired bone  
24 marrow failure diseases; and

25 (v) any other factors pertaining to acquired bone marrow  
26 failure diseases determined appropriate by the Secretary; and

1 (C) be made available:

2 (i) to the general public; and

3 (ii) to researchers to facilitate further research into the causes  
4 of, and treatments for, acquired bone marrow failure diseases in  
5 accordance with standard practices of the Centers for Disease  
6 Control and Preventions.

7 (b) *Advisory Committee.* –

8 (1) *Establishment.* – Not later than 6 months after the date of effectivity of  
9 this Act, the Secretary, shall establish an advisory committee, to be known as the  
10 Advisory Committee on Acquired Bone Marrow Failure Diseases.

11 (2) *Members.* – The members of the Advisory Committee on Acquired  
12 Bone Marrow Failure Diseases shall be appointed by the Secretary, and shall  
13 include at least one representative from each of the following:

14 (A) A national patient advocacy organization with experience  
15 advocating on behalf of patients suffering from acquired bone marrow  
16 failure diseases.

17 (B) The centers for Disease Control and Prevention.

18 (C) Clinicians with experience in diagnosing or treating acquired  
19 bone marrow failure diseases; and medical data registries.

20 (D) Epidemiologists who have experience with data registries.

21 (E) Publicly or privately funded researchers who have experience  
22 researching acquired bone marrow failure diseases.

23 (3) *Responsibilities.* – The Advisory Committee on Acquired Bone Marrow  
24 Failure Diseases shall provide recommendations to the Secretary on the  
25 establishment and maintenance of the National Acquired Bone Marrow Failure

1 Disease Registry, including recommendations on the collection, maintenance, and  
2 dissemination of data.

3 (4) *Public Availability.* – The Secretary shall make the recommendations of  
4 the Advisory Committee on Acquired Bone Marrow Failure Disease publicly  
5 available.

6 (c) *Grants.* – The Secretary may award grants to, and enter into contracts and  
7 cooperative agreements with, public or private nonprofit entities for the management of,  
8 as well as the collection, analysis, and reporting of data to be included in, the National  
9 Acquired Bone Marrow Failure Disease Registry.

10 SECTION 4. *Authorization of Appropriations.* – To carry out the provisions of this  
11 Act, there are authorized to be appropriated such sums as may be necessary for each  
12 fiscal year.

13 SECTION 5. *Separability Clause.* – If any provision of this Act shall be declared  
14 unconstitutional, any other provision not affected thereby shall remain in full force and  
15 effect.

16 SECTION 6. *Repealing Clause.* – All laws, decrees, orders, rules and regulations,  
17 or parts thereof inconsistent with this Act are hereby repealed or amended accordingly.

18 SECTION 7. *Effectivity.* – This Act shall take effect fifteen (15) days after its  
19 publication in at least two (2) newspapers of general circulation.

Approved,