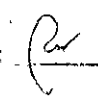


FIFTEENTH CONGRESS OF THE REPUBLIC)
OF THE PHILIPPINES)
Second Regular Session)

Office of the Secretary

12 MAR -5 P 3:30

SENATE
S. No. 3144

RECEIVED: 

Introduced by Senator Miriam Defensor Santiago

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 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 bills directs the Secretary of Health to establish a National Acquired Bone Marrow Failure Disease Registry on acquired bone marrow failure diseases.

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MIRIAM DEFENSOR SANTIAGO

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

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

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

9 (i) identify the incidence and prevalence of acquired bone marrow
10 failure diseases in the Philippines;

11 (ii) be used to collect and store data on acquired bone marrow failure
12 diseases, including data concerning:

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

17 (b) the genetic and environmental factors that may be
18 associated with developing acquired bone marrow failure diseases;

19 (c) treatment approaches for dealing with acquired bone
20 marrow failure diseases;

21 (d) outcomes for individuals treated for acquired bone marrow
22 failure diseases; and

23 (e) any other factors pertaining to acquired bone marrow
24 failure diseases determined appropriate by the Secretary; and

25 (iii) be made available:

26 (a) to the general public; and

27 (b) to researchers to facilitate further research into the causes
28 of, and treatments for, acquired bone marrow failure diseases in

1 accordance with standard practices of the Centers for Disease Control and
2 Preventions.

3 (B) *Advisory Committee.* –

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

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

10 (i) A national patient advocacy organization with experience
11 advocating on behalf of patients suffering from acquired bone marrow failure
12 diseases.

13 (ii) The centers for Disease Control and Prevention.

14 (iii) Clinicians with experience in diagnosing or treating acquired bone
15 marrow failure diseases; and medical data registries.

16 (iv) Epidemiologists who have experience with data registries.

17 (v) Publicly or privately funded researchers who have experience
18 researching acquired bone marrow failure diseases.

19 (3) *Responsibilities.* – The Advisory Committee on Acquired Bone Marrow
20 Failure Diseases shall provide recommendations to the Secretary on the establishment
21 and maintenance of the National Acquired Bone Marrow Failure Disease Registry,
22 including recommendations on the collection, maintenance, and dissemination of data.

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

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

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

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

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

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

Approved,

/fldp 1march2012