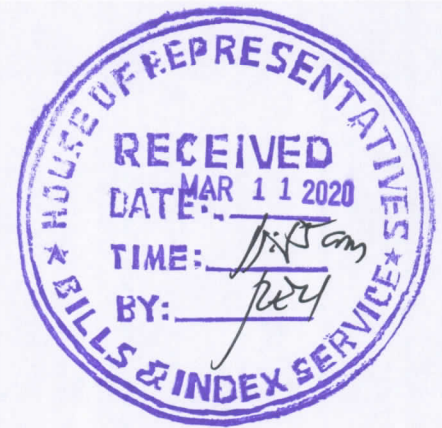


Republic of the Philippines
HOUSE OF REPRESENTATIVES
Quezon City

EIGHTEENTH CONGRESS
First Regular Session

HOUSE BILL No. 6560



Introduced by
**BAYAN MUNA Representatives FERDINAND R. GAITE,
CARLOS ISAGANI T. ZARATE and EUFEMIA C. CULLAMAT**

**AN ACT PROVIDING A STANDARD OF CARE FOR THE
TREATMENT OF PERSONS WITH BLEEDING DISORDERS, ESTABLISHING
TREATMENT CENTERS AND
APPROPRIATING FUNDS THEREFOR**

EXPLANATORY NOTE

Article 25 of the Universal Declaration of Human Rights provides: "Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control."

In the Philippines, about one million Filipinos are affected by Hemophilia, von Willebrand Disease and other bleeding disorders. Data from the World Federation of Hemophilia (WFH) suggests that more than 90% of the cases remain undiagnosed as only around 1,500 have been registered with the Philippine Hemophilia Foundation. There is also an obvious lack of awareness and understanding on this group of medical conditions.

Bleeding disorder is a genetic condition where the blood does not clot properly. It is caused by deficiency of proteins in the blood called clotting factors. There are 13 factors in the blood, and when one of it is missing or is deficient, it results in a bleeding disorder.

People with bleeding disorders can bleed for longer than normal, and some may experience spontaneous bleeding into joints, muscles, or other parts of their bodies. Women with bleeding disorders may experience menorrhagia (excessive menstruation) and post-partum hemorrhage, on top of other bleeding problems.

The most known of this group of medical conditions is Hemophilia, classified as Hemophilia A (Factor VIII deficiency) and Hemophilia B (Factor IX deficiency), which occurs mostly in males. But the most prevalent is von Willebrand Disease (deficiency in von Willebrand factor), which affects around 1 percent of the population – both males and females. Other factor deficiency disorders are: I, II, V, VII, X, XI, XIII. (Source: World Federation of Hemophilia)

Bleeding disorders like Hemophilia, von Willebrand Disease and other factor deficiencies are usually inherited and genetic. Thus, there may be multiple members in a family affected by the condition and they will have it for life. There is no known cure yet for bleeding disorders.

The World Health Organization and the Department of Health cited post-partum hemorrhage as one of the top causes of maternal deaths. Incidentally, the Philippines did not meet the

1 Millennium Development Goal on maternal health. It is very possible that a big percentage of
2 those mothers who died of post-partum hemorrhage had undiagnosed bleeding disorders. Many
3 patients with hemophilia probably died without ever being diagnosed or treated.

4 Bleeding disorders are treated by replacing the missing or deficient factors either through blood
5 products such as cryo-precipitate, cryo-supernatant, fresh frozen plasma, packed red blood cells
6 (RBC) and whole blood or by manufactured plasma-derived factor concentrates and
7 recombinant (genetically engineered) factor concentrates.

8 In developed countries, the life expectancy of persons with hemophilia is close to that of healthy
9 persons. Other countries like India and Malaysia give free treatment to their citizens who have
10 bleeding disorders. Many Filipinos with hemophilia on the other hand grow up with disabilities
11 mostly due to prolonged bleeding into joints as a result of lack of access to treatment.

12 According to Hemophilia Advocates - Philippines, hemophilia care in our country is sub-optimal
13 and inadequate. Filipinos with hemophilia and bleeding disorders rely heavily on humanitarian
14 aid for treatments. Many of them suffer with chronic pain and deformities in the joints because
15 of lack of access to proper treatment. Availability of factor concentrates in the country is also
16 inconsistent.

17 The government has no program for hemophilia. Hemophilia is not included among rare
18 diseases covered by Republic Act 10747 or the Rare Diseases Act. Likewise, it is not covered by
19 the Z benefit package of Philhealth for health conditions with very expensive treatments and
20 prolonged hospitalization.

21 The cost of treatment is very high, and therefore, inaccessible to majority of Filipino patients yet
22 the government provides very minimal support. A mild bleed in the joints can cost P30,000 to
23 P50,000 per treatment. Yet, Philhealth coverage only provides P2,000 per incident, not even
24 enough for a bag of blood for transfusion which costs P5,700 per bag.

25 The challenge is to find ways to develop and implement a viable, practical and sustainable
26 hemophilia care programs in the country. If hemophilia is to be diagnosed and treated adequately
27 in our country, available treatment options must be backed by support and commitment from
28 our government and must be performed within the context of the national healthcare system.

29 This bill seeks to provide medical and financial support to patients affected with this condition
30 by providing treatment facilities, increasing Philhealth coverage, inclusion of Hemophilia in
31 assessment and screening tools and to increase public awareness to help in early diagnosis and
32 timely intervention.

33 Thus, the immediate passage of this bill is earnestly sought.

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35 *Approved,*

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39 **REP. FERDINAND R. GAITE**

Bayan Muna Partylist

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44 **REP. CARLOS ISAGANI T. ZARATE**

Bayan Muna Partylist

REP. EUFEMIA C. CULLAMAT

Bayan Muna Partylist

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Republic of the Philippines
HOUSE OF REPRESENTATIVES
Quezon City

EIGHTEENTH CONGRESS

First Regular Session

6560

HOUSE BILL No. ____

Introduced by

BAYAN MUNA Representatives FERDINAND R. GAITE
CARLOS ISAGANI T. ZARATE and EUFEMIA C. CULLAMAT

AN ACT PROVIDING A STANDARD OF CARE
FOR THE TREATMENT OF PERSONS WITH BLEEDING DISORDERS,
ESTABLISHING TREATMENT CENTERS
AND APPROPRIATING FUNDS THEREFOR

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

Section 1. *Short Title.* – This Act shall be known as the “*Bleeding Disorder Standards of Care Act of 2020.*”

Section 2. *Declaration of Policy.* – It is hereby declared the policy of the State:

- (1) To ensure the adequate treatment of hemophilia at the lowest possible cost and endeavor to make them available for free to indigent patients;
- (2) To ensure the establishment of treatment centers in public hospitals; and
- (3) To establish a standard of care so that patients with severe bleeding disorders can receive necessary and appropriate medical care.

Section 3. *Definitions.* – The following words and phrases when used in this Act shall have the meanings given to them in this Section unless the context clearly indicates otherwise:

- (1) ***"Bleeding Disorder"*** - A medical condition characterized by a severe deficiency or absence of one or more essential blood clotting proteins in the human blood, often called factors, including all forms of hemophilia, von Willebrand disease and other bleeding disorders which result in uncontrollable bleeding or abnormal blood clotting.
- (2) ***"Blood clotting product"*** - An intravenously administered medicine manufactured from human plasma, recombinant biotechnology techniques and other processes, approved for distribution by the BFAD and which is used for the treatment and prevention of symptoms associated with bleeding disorders. The term includes, but is not limited to:
 - (A) Factor VIIa, Factor VIII and Factor IX products;
 - (B) Von Willebrand Factor products;
 - (C) Prothrombin complex concentrates;
 - (D) Activated prothrombin complex concentrates;
 - (E) Other products approved by the BFAD for the treatment of bleeding

disorders and associated inhibitors.

(3) **"Indigent Patient"** – Any patient deemed unable to pay for services and or medical treatment, laboratory testing of blood and/or coagulation studies, or blood coagulating products and/or ancillary infusion equipment.

(4) **"DOH"** – refers to the Department of Health.

(5) **"BFAD"** – refers to the Bureau of Food and Drugs.

(6) **"Hemophilia"** – A human bleeding disorder caused by a hereditary deficiency of the Factor VIII, Factor IX or Factor XI blood clotting protein in human blood.

(7) **"von Willebrand disease"** – A human bleeding disorder caused by a hereditary deficiency or abnormality of the von Willebrand Factor in human blood.

Section 4. Hemophilia Treatment Facilities. – The State shall establish hemophilia treatment facilities in key cities and regions nationwide in designated hospitals with Cancer and Hematology Departments.

Each Hemophilia Treatment Facilities shall provide to all hemophilia patients:

(1) Care by qualified hematologists and medical doctors and shall also provide free of charge the necessary blood clotting products and ancillary infusion equipment necessary for the infusion of such blood clotting products;

(2) A room exclusively for hemophilia patients; and

(3) A clinical coagulation laboratory for the screening, diagnosis, provisional diagnosis and treatment of bleeding disorders or suspected bleeding disorders and such services shall be provided free of charge to all indigent patients.

Section 5. Inclusion of Hemophilia in Patients Assessment Tools. Hemophilia and other bleeding disorders shall be included in patients' history and assessment tools including familial history and history or presence of bleeding episodes.

Section 6. Inclusion of Hemophilia Screening in Newborn Screening. Screening tests for hemophilia shall be included in the comprehensive newborn screening tests.

Section 7. Increase in Philhealth Benefits. – Philhealth shall review and increase as appropriate based on the recommendations of the Department of Health and Hemophilia patients group the benefit for bleeding disorders. The benefit package shall include, among others, blood transfusion and/or injection of blood coagulating products, and laboratory and diagnostic procedures.

Section 8. Health Education and Public Awareness. – The Department of Health shall provide educational materials to increase public awareness on hemophilia and other bleeding disorders.

Section 9. Funding. – The amount necessary for the initial implementation of this Act shall be sourced from the current budget of the Department of Health. Thereafter, the funds necessary for the continuous implementation of this Act in the ensuing years shall be included in the General Appropriations Act.

The treatment facilities are allowed to use five percent (5%) of the amount given to it for the maintenance of the rooms that will be used exclusively for hemophilia patients. However, ninety percent (90%) of the amount shall be used exclusively for necessary blood clotting products and ancillary infusion equipment necessary for the infusion of such blood clotting products to hemophilia patients. The remaining five percent (5%) shall be used for blood screening of hemophilia patients.

1 Each treatment facility shall submit an annual report to the DOH on how the amount given to it
2 is used.

3 **Section 10. *Regulations.*** – Within sixty (60) days from the approval of this Act, the
4 Department of Health (DOH) shall, in consultation with hemophilia groups, promulgate the
5 Implementing Rules and Regulations (IRR) to carry out the provisions of this Act.

6 **Section 11. *Separability Clause.*** – If for any reason, any provision of this Act is declared
7 unconstitutional or invalid, the other parts or provisions hereof which are not affected thereby
8 shall continue to be in full force and effect.

9 **Section 12. *Effectivity Clause.*** – This Act shall take effect on the fifteenth day following its
10 publication in the Official Gazette or any newspaper of national circulation.

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12 *Approved,*