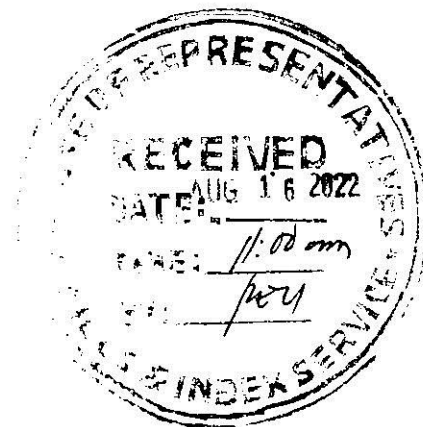


Republic of the Philippines
HOUSE OF REPRESENTATIVES
Batasan Hills, Quezon City

NINETEENTH CONGRESS
First Regular Session

HOUSE BILL No. 3651



Introduced by
ACT Teachers Party-List Rep. FRANCE L. CASTRO,
GABRIELA Women's Party Rep. ARLENE D. BROSAS,
and KABATAAN Party-List Rep. RAOUL DANNIEL A. MANUEL

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 states that “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.”

The World Federation of Hemophilia estimated that there could be some 10,000 Filipinos affected by hemophilia and around one million others with von Willebrand disease and other bleeding disorders. However, their data suggests that more than 90% of the cases remain undiagnosed as only 1,650¹ have been reported by the Hemophilia Philippines Foundation Inc. There is also an obvious lack of awareness and understanding of 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 periods than normal, and some

¹ World Federation of Hemophilia. Report on the Annual Global Survey 2020. World Federation of Hemophilia website, October 2021. <https://www.wfah.org/publications/files/pdf-2015.pdf>

may experience spontaneous bleeding into joints, muscles, or other parts of their bodies. Women with bleeding disorders may experience menorrhagia (excessive menstruation) and postpartum hemorrhage, on top of the other bleeding problems.

According to the WFH, 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.

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 postpartum hemorrhage as one of the top causes of maternal deaths. Incidentally, the Philippines did not meet the Millennium Development Goal on maternal health. It is very possible that a big percentage of those mothers who died of postpartum hemorrhage had undiagnosed bleeding disorders. Many patients with hemophilia probably died without ever being diagnosed or treated.

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

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

According to Hemophilia Advocates - Philippines, hemophilia care in our country is sub-optimal and inadequate. Very few hospitals have the capability and equipment to treat patients with bleeding disorders and most of them are private hospitals based in urban areas. Filipinos with hemophilia and bleeding disorders rely heavily on humanitarian aid for treatments. Many of them suffer with chronic pain and deformities in the joints because of lack of access to proper treatment. Availability of factor concentrates in the country is also inconsistent.

The government has no program for hemophilia. Hemophilia is not included among rare diseases covered by Republic Act No. 10747 or the Rare Diseases Act. Likewise, it is not covered by the Z Benefit Package of the Philippine Health Insurance Corp. (PhilHealth) for health conditions with very expensive treatments and prolonged hospitalization.

The cost of treatment is very high, and therefore, inaccessible to the majority of

Filipino patients yet the government provides very minimal support. A mild bleed in the joints can cost ₱30,000 to ₱50,000 per treatment. Yet, the PhilHealth coverage only provides ₱2,000 per incident, not even enough for a bag of blood for transfusion which costs ₱5,700 per bag.

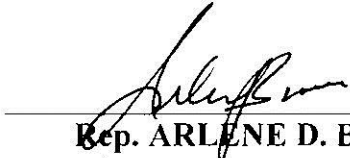
The challenge is to find ways to develop and implement viable, practical and sustainable health programs for patients with bleeding disorders in the country. If hemophilia and other bleeding disorders are to be diagnosed and treated adequately in our country, available treatment options must be backed by support and commitment from our government and must be performed within the context of the national health care system.

This Bill was first filed by Bayan Muna Party-List during the 18th Congress as House Bill 6560, which seeks to provide medical and financial support to patients affected with these condition by providing treatment facilities, increasing PhilHealth coverage, inclusion of hemophilia in assessment and screening tools and to increase public awareness to help in early diagnosis and timely intervention.

Thus, the immediate passage of this Bill is earnestly sought.



Rep. FRANCE L. CASTRO
ACT Teachers Party-List



Rep. ARLENE D. BROSAS
GABRIELA Women's Party



Rep. RAOUL DANNIEL A. MANUEL
KABATAAN Party-List

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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 2022.***”

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

- (1) To ensure the adequate treatment of hemophilia and other bleeding disorders 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 refers to 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 refers to 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 refers to 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 refers to 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) PhilHealth refers to the Philippine Health Insurance Corp.
- (8) von Willebrand disease refers to a human bleeding disorder caused by a hereditary deficiency or abnormality of the von Willebrand Factor in human blood.

Section 4. Bleeding Disorder Treatment Facilities. – The State shall establish bleeding disorder treatment facilities in key cities, regions and nationwide in designated hospitals with Cancer and Hematology Departments.

Each treatment facility shall provide the following to all patients with bleeding disorder:

- (1) Care by qualified hematologists and medical doctors;
- (2) Free necessary blood clotting products and ancillary infusion equipment for the infusion of such blood clotting products;
- (3) A room exclusively for the patients with bleeding disorder; and
- (4) A clinical coagulation laboratory for the screening, diagnosis, provisional diagnosis and treatment of bleeding disorders or suspected bleeding disorders: *Provided*, That such services that shall be provided free of charge to all indigent patients.

Section 5. Inclusion of Hemophilia and Other Bleeding Disorders 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.* – The PhilHealth shall review and increase the amount of the benefit packages for bleeding disorders in consultation with the DOH and the stakeholders. 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 DOH shall provide educational materials and conduct health education campaigns 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 DOH. 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 up to five percent (5%) of the fund for the maintenance of the rooms that will be used exclusively for patients with bleeding disorders. *Provided, That* 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 patients with bleeding disorders.

Each treatment facility shall submit an annual report to the DOH on the utilization of the fund.

Section 10. *Implementing Rules and Regulations.* – Within ninety (90) days from the effectivity of this Act, the DOH, in consultation with the stakeholders, shall issue the necessary rules and regulations to implement the provisions of this Act.

Section 11. *Separability Clause.* – If any provision or part hereof is declared unconstitutional or invalid, the remainder of the law or the provision not otherwise affected shall continue to be in full force and effect.

Section 12. *Effectivity Clause.* – This Act shall take effect fifteen (15) days after its publication in the *Official Gazette* or in a newspaper of national circulation.

Approved,