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REPUBLIC OF KENYA

THE NATIONAL ASSEMBLY

THIRTEENTH PARLIAMENT – FIFTH SESSION – 2026

DIRECTORATE OF DEPARTMENTAL COMMITTEES

DEPARTMENTAL COMMITTEE ON HEALTH

.....

REPORT ON PUBLIC PETITION NO. 001 OF 2026 REGARDING MANAGEMENT OF HAEMOPHILIA AND OTHER BLEEDING DISORDERS AMONG PATIENTS AND CHILDREN IN THE COUNTRY

THE NATIONAL ASSEMBLY
PAPERS LAID
DATE: 23 JUN 2026 DAY. TUESDAY
TABLED BY: Hon. Dr. James Nyikal MP Deputy ~~Leader of Majority~~ Party Chair, DC Health
CLERK-AT THE-TABLE: P Muiga

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CHAIRPERSON'S FOREWORD

It is my honour, on behalf of the Departmental Committee on Health and pursuant to Standing Order 227, to present to the House this Report on Public Petition No. 001 of 2026 on the Management of Haemophilia and Other Bleeding Disorders in Kenya.

The Petition was submitted by Mr. James Kago, Treasurer of the Haemophilia Association of Kenya, on behalf of haemophilia patients across the country. It was tabled by the Rt. Hon. Dr. Moses M. Wetang'ula, EGH, MP, Speaker of the National Assembly on 8th March 2026, pursuant to Standing Order 225(2)(a), and subsequently committed to this Committee for consideration under Standing Order 221(1).

The Petitioners made the following prayers to the National Assembly:

i. Recognition of clotting factor concentrates as essential medicines for both adult and paediatric haemophilia treatment, to ensure their consistent and sustainable availability in Kenya.

ii. The Government to strengthen infrastructure and capacity by establishing additional haemophilia treatment centres across the country, enhancing diagnostic capacity, improving healthcare worker training, including specialized pediatric care. reviewing medical curricula to incorporate management of haemophilia and other bleeding disorders, and increasing funding for public awareness, particularly in relation to early childhood screening.

iii. Formal recognition of haemophilia as a disabling condition to enable registration with the National Council for Persons with Disabilities (NCPWD), as well as inclusion of haemophilia treatment under the Social Health Insurance Fund (SHIF).

iv. Any other measures that the National Assembly deems appropriate to address the plight of persons living with haemophilia in Kenya.

The Petition highlights the significant burden of haemophilia in Kenya. Haemophilia affects an estimated 4,500 to 5,500 Kenyans, yet only 1,265, roughly 23 percent, have been formally identified. Current donor support through the World Federation of Haemophilia, valued at approximately USD 20 million annually, covers only 30 percent of required clotting factor concentrates. The Memorandum of Understanding governing this support expires in early 2027. Without urgent domestic financing and a sustainable supply chain, Kenya faces a preventable humanitarian crisis that will leave thousands of patients without life-saving treatment.

In response, the Committee recommends that the Ministry of Health fast-track the inclusion of clotting factor concentrates in the Kenya Essential Medicines List, develop and implement a comprehensive haemophilia benefits package under SHIF, classify haemophilia as a disabling condition, expand treatment infrastructure to underserved counties, reform medical training curricula to include training on the management of haemophilia and other bleeding disorders, introduce mandatory antenatal screening for bleeding disorders, fully operationalize the a national patient registry and integrate psychosocial support into the national health system.

The Committee is grateful to the Offices of the Speaker and the Clerk of the National Assembly for the logistical and technical support accorded to it during the consideration of

the Petition. Additionally, I wish to express my appreciation to the Honourable Members of the Committee and all those who contributed in the processing of this petition.

Pursuant to Standing Order 227(2), I present to this this report to the House for consideration and adoption by the House.

Sign..... **Date**.....22/6/2026.....

HON. DR. NYIKAL JAMES WAMBURA, CBS, MP
CHAIRPERSON, DEPARTMENTAL COMMITTEE ON HEALTH

CHAPTER ONE

1.0 PREFACE

1.1 Establishment and Mandate of the Committee

1. The Departmental Committee on Health is one of the Departmental Committees of the National Assembly established under Standing Order 216 whose mandates pursuant to the Standing Order 216 (5) are as follows:

   a) To investigate, inquire into, and report on all matters relating to the mandate, management, activities, administration, operations and estimates of the assigned ministries and departments;

   b) To study the programme and policy objectives of ministries and departments and the effectiveness of the implementation;

   c) on a quarterly basis, monitor and report on the implementation of the national budget in respect of its mandate;

   d) To study and review all legislation referred to it;

   e) To study, assess and analyse the relative success of the ministries and departments as measured by the results obtained as compared with their stated objectives;

   f) To investigate and inquire into all matters relating to the assigned ministries and departments as they may deem necessary, and as may be referred to them by the House;

   g) To vet and report on all appointments where the Constitution or any law requires the National Assembly to approve, except those under Standing Order 204 (Committee on Appointments);

   h) To examine treaties, agreements and conventions;

   i) To make reports and recommendations to the House as often as possible, including recommendations of proposed legislation;

   j) To consider reports of Commissions and Independent Offices submitted to the House pursuant to the provisions of Article 254 of the Constitution; and

   k) To examine any questions raised by Members on a matter within its mandate.

1.2 Subjects under the Committee

2. In accordance with the Second Schedule of the Standing Orders, the Committee is mandated to consider matters related to health, medical care and health insurance, including universal health coverage.

1.3 Oversight

3. In executing its mandate, the Committee on Health oversees the:
   i. State Department for Medical Services; and
   ii. State Department for Public Health and Professional Standards.

1.4 Committee Membership

4. The Departmental Committee on Health was constituted by the House on 27th October 2022 and comprises the following Members:

Chairperson
Hon. Dr. Nyikal James Wambura, MP
Seme Constituency
ODM Party

Vice-Chairperson
Hon. Ntwiga, Patrick Munene MP
Chuka/Igambang'ombe Constituency
UDA Party

Hon. Owino Martin Peters, MP
Ndhiwa Constituency
ODM Party

Hon. Muge Cynthia Jepkosgei, MP
Nandi (CWR)
UDA Party

Hon. Wanyonyi Martin Pepela, MP
Webuye East Constituency
Ford Kenya Party

Hon. Kipng'ok Reuben Kiborek , MP
Mogotio Constituency
UDA Party

Hon. (Dr) Robert Pukose, MP
Endebess Constituency
UDA Party

Hon. Kibagendi Antoney, MP
Kitutu Chache South Constituency
ODM Party

Hon. Julius Ole Sunkuli Lekakeny, MP
Kilgoris Constituency
KANU

Hon. Maingi Mary, MP
Mwea Constituency
UDA Party

Hon. Mathenge Duncan Maina, MP
Nyeri Town Constituency
UDA Party

Hon. Lenguris Pauline, MP
Samburu (CWR)
UDA Party

Hon. Oron Joshua Odongo, MP
Kisumu Central Constituency
ODM Party

Hon. (Prof.) Jaldesa Guyo Waqo, MP
Moyale Constituency
UPIA Party

Hon. Mukhwana Titus Khamala, MP
Lurambi Constituency
ODM Party

1.5 Committee Secretariat

5. The Committee is facilitated by the following staff secretariat:

Mr. Adan Gindicha
Principal Clerk Assistant II-HOD

Mr. Ellam Omuhinda
Clerk Assistant III

Ms. Gladys Jepkoech Kiprotich
Clerk Assistant III

Ms. Marlene Ayiro
Principal Legal Counsel I

Ms. Faith Chepkemoi
Legal Counsel II

Mr. Hiram Kimuhu
Fiscal Analyst II

Mr Eric Lungai
Hansard Reporter II

Ms. Sheila Chebotibin
Principal Serjeant-At-Arms

Ms. Abigael Muinde
Research Officer III

Ms. Mercylyn Kerubo
Audio Recording Officer

Mr.Daniel Psirmoi
Media Relations Officer III

CHAPTER TWO

2.0 BACKGROUND OF THE PETITION

2.1 Introduction

6. Public Petition No. 001 of 2026 Regarding Management of Haemophilia and Other Bleeding Disorders Among Patients and Children in the Country by Mr. James Kago (Treasurer of the Haemophilia Association) was presented to the House on 8th March 2026, the Rt. Hon. (DR.) Moses M. Wetang'ula, EGH, MP, Speaker of the National Assembly, on behalf of Haemophilia patients in the country.

7. This was pursuant to Article 119 of the Constitution, which accords any person the right to petition Parliament to consider any matters within its authority. Further, Standing Order 225(2)(b) requires the Speaker to report to the House any petition other than those presented by a member. The Petition was therefore committed to the Departmental Committee on Health for consideration and reporting to the House.

8. The Petition was presented by Mr. James Kago, who serves as the Treasurer of the Haemophilia Association. The Petition highlights the significant burden of haemophilia in Kenya, noting that the condition affects approximately one in every 10,000 individuals. It is estimated that about 4,500 people in Kenya are living with haemophilia, a large proportion of whom are children. However, only 1,265 patients (representing about 23 per cent) have been formally identified. Treatment coverage remains critically inadequate, with current donation programmes providing only 30 per cent of the required clotting factor levels. This leaves a 70 per cent deficit, and the situation is expected to worsen as the donation programme is projected to end within the next two years, posing an imminent public health crisis.

9. The petitioner raised the following core concerns:

   i. Haemophilia is described as a life-threatening condition characterized by frequent and unpredictable bleeding episodes, which often result in disabling joint disease, chronic pain, missed opportunities for education and employment, and reduced life expectancy.
   ii. Access to treatment is a major challenge, as it is highly specialized, costly, and time-consuming, placing considerable physical, financial, emotional, and psychological strain on affected individuals and their families.
   iii. There are significant data gaps due to fragmented and uncoordinated information systems, particularly affecting the identification and management of children with the condition.
   iv. The country also faces inadequate infrastructure, with only a few fully operational haemophilia treatment centres, alongside persistent shortages of clotting factor concentrates, forcing reliance on less safe blood-derived products.

10. In consideration of the Petition, the Committee engaged the Petitioners and the Cabinet Secretary, Ministry of Health.

2.2 The Petitioner's Prayers

11. The Petitioners made the following prayers to the National Assembly—

i. Recognition of clotting factor concentrates as essential medicines for both adult and paediatric haemophilia treatment, to ensure their consistent and sustainable availability in Kenya.

ii. The Government to strengthen infrastructure and capacity by establishing additional haemophilia treatment centres across the country, enhancing diagnostic capacity, improving healthcare worker training, including specialized pediatric care. reviewing medical curricula to incorporate management of haemophilia and other bleeding disorders, and increasing funding for public awareness, particularly in relation to early childhood screening.

iii. Formal recognition of haemophilia as a disabling condition to enable registration with the National Council for Persons with Disabilities (NCPWD), as well as inclusion of haemophilia treatment under the Social Health Insurance Fund (SHIF).

iv. Any other measures that the National Assembly deems appropriate to address the plight of persons living with haemophilia in Kenya.

CHAPTER THREE

3.0 STAKEHOLDER SUBMISSIONS ON THE PETITION

12. The Committee convened a sitting on Tuesday, 21st April, 2026, at which it received oral and written submissions from Mr. James Kago who serves as the Board Treasurer of the Haemophilia Association and engaged in substantive deliberations. Mr. Kago was accompanied by haemophilia patients and caregivers and clinicians.

13. The Ministry of Health, through the Cabinet Secretary, Hon. Aden Duale submitted a formal response on the issues raised in the Petition dated 1st April, 2025.

3.1 Submission by Mr. James Kago, Treasurer, the Kenya Haemophilia Association (KHA)

14. The Kenya Haemophilia Association (KHA) was established by clinicians at Kenyatta National Hospital to support haemophilia care. Only 1,265 patients have been identified out of an estimated 5,000, leaving 3,800 undiagnosed. Treatment is extremely costly: Factor concentrate: Kshs. 50,000 per injection. Advanced treatment: Kshs. 1 million/month per patient (limited to 34 patients under trial). Majority of patients rely on on-demand treatment and not on preventive care. There is heavy reliance on donor support (KES 1.5 billion annually), with risk due to an expiring MoU and donor fatigue.

a) Background: The Kenya Haemophilia Association (KHA)

15. The Kenya Haemophilia Association (KHA) was established in Nairobi in 1979 and recognized in 1992 as a National Member Organization (NMO) by the World Federation of Haemophilia (WFH). This recognition mandates KHA as the official patient organization representing individuals living with haemophilia and other inherited bleeding disorders in Kenya.

16. KHA plays a central role in advocacy, patient support, capacity building, and collaboration with key stakeholders to improve access to diagnosis, treatment, and comprehensive care nationwide.

b) Haemophilia

17. Haemophilia is a sex-linked inherited bleeding disorder affecting approximately 1 in every 10,000 individuals. In Kenya, about 1,265 patients have been identified and enrolled out of an estimated 5,500 individuals living with the condition.
18. The disorder may also arise spontaneously due to mutations in the X chromosome. There are three main types:

    i. Haemophilia A – deficiency of clotting factor VIII
    ii. Haemophilia B – deficiency of clotting factor IX
    iii. Haemophilia C – deficiency of clotting factor XI

19. Clinically, haemophilia manifests through prolonged or spontaneous bleeding episodes, particularly into joints and vital organs. Recurrent bleeding can result in chronic joint damage, disability, and reduced quality of life if not adequately managed.

c) Current Challenges

20. Hemophilia care in Kenya faces significant systemic, financial, and structural challenges. The condition is currently not covered under the Social Health Authority (SHA), Kenya's national health insurance framework, forcing patients to meet the full cost of treatment out-of-pocket, which creates a prohibitive financial burden.

21. A single infusion visit at Kenyatta National Hospital costs approximately KES 310, while a clinician consultation costs about Kshs. 1,450 per visit. Patients typically require hospital visits two to three times per month, or more frequently during bleeding episodes, and severe cases may require hospital admissions lasting over a month, resulting in cumulative costs that are unaffordable for most Kenyan families.

22. Kenya is also heavily dependent on donor-funded clotting factor concentrates through a Memorandum of Understanding with the World Federation of Hemophilia (WFH), signed in 2021 and set to expire in early 2027. The donation, valued at approximately USD 20 million annually, provides only about 30% of the required clotting factor levels. Concerns have been raised regarding donor fatigue and shifting global economic conditions, which may affect renewal of the agreement. In the event that the MOU is not renewed, patients risk being left without treatment.

23. The WFH has proposed a cascaded co-investment model in which the Government of Kenya would contribute 25% in the first year, with donor support covering the remaining 75%, and gradually increase its contribution until full ownership of procurement is achieved.

24. Recurrent joint bleeds result in permanent musculoskeletal damage and deformities, with patients demonstrating severely limited joint mobility, in some cases unable to flex beyond 45 degrees. Despite these visible impairments, haemophilia is not formally classified as a disabling condition in Kenya, thereby denying patients access to disability benefits and protections.

25. Additionally, treatment services remain highly centralized, with most patients required to travel to Nairobi or a few regional facilities. Counties such as Kirinyaga and Embu lack treatment centres, forcing patients to travel long distances, sometimes as far as Murang'a, contrary to the KHA recommendation that no patient should travel more than one hour to access care.

26. Clinical awareness and training on haemophilia remain inadequate, as the condition is not sufficiently integrated into medical and nursing curricula. Consequently, clinicians frequently misdiagnose haemophilia, often attributing symptoms to other conditions such as brucellosis. Many healthcare providers, including haematologists and general practitioners, lack the necessary expertise to manage the condition effectively, with most training initiatives funded by international donors rather than national institutions. Furthermore, women with bleeding disorders are not routinely screened before labour, contributing to preventable maternal deaths from postpartum haemorrhage.

27. The socioeconomic burden on affected families is profound. Caregivers, predominantly mothers, often lose employment due to repeated hospital visits and emergency admissions, leading to loss of income and lack of pension security. In many

cases, fathers abandon families with haemophilic children, leaving single mothers as sole caregivers without financial support. Children frequently miss school due to illness, resulting in disrupted education and, in some cases, inability to complete formal schooling. Adults living with untreated haemophilia are often unable to engage in productive employment and may be confined to rural settings without adequate care.

28. An estimated 3,800 Kenyans living with haemophilia remain undiagnosed, contributing to preventable deaths. Testimonies presented included cases of children dying from untreated head bleeds before diagnosis, patients enduring years of misdiagnosis, and boys dying during traditional circumcision due to undiagnosed bleeding disorders.

29. Additionally, maternal deaths have been reported among women with undiagnosed bleeding disorders such as Von Willebrand disease, further underscoring the urgent need for improved diagnosis and care.

d) Key Petition and Requests

30. The Kenya Haemophilia Association formally requests Parliament to consider and support several key interventions. These include the inclusion of haemophilia and related bleeding disorders under SHA as congenital and critical conditions to ensure coverage for treatment, consultations, infusions, and hospital admissions; and the formal recognition of haemophilia as a disabling condition under Kenyan law to enable access to government disability-related services, relief programmes, and protections.

31. The Association further calls on the Government of Kenya to enter into a co-investment agreement with WFH under the proposed cascaded model to progressively assume full responsibility for the procurement of clotting factor concentrates.

32. Additional requests include the expansion of accredited haemophilia treatment centres to underserved counties to ensure that no patient travels more than one hour to access care; the integration of haemophilia management and bleeding disorder recognition into standard medical and nursing training curricula; and the introduction of mandatory screening protocols for bleeding disorders in maternal healthcare to reduce preventable maternal mortality.

33. The Association also emphasizes the need for a structured national awareness programme to support early identification and referral of undiagnosed patients, particularly in rural areas and communities practising traditional circumcision, as well as the provision of dedicated psychosocial support services for patients and their families within the national health system.

3.2 Submission by Haemophilia Patients, Caregivers and Clinician

34. The Committee also received oral submissions from the following three persons on 21st April 2026.

a) Ms. Irene Wakaba – A representative of Parents and Caregiver of Haemophilic Children

35. Ms. Wakaba, a teacher and mother of a 10-year-old haemophilic child, shared a personal account of loss of her first haemophilic child who died at three and a half years old from a head bleed due to delayed diagnosis. She described the physical, financial and psychological burden borne by families, particularly mothers who often become sole caregivers. These caregivers also experience frequent job loss, poverty, and mental health deterioration. She also highlighted the impact of haemophilia on female carriers, who experience prolonged menstrual bleeding which is costly.

b) **Mr. Christopher Koisikir – A Patient Representative**

36. Mr. Koisikir, diagnosed with haemophilia at the age of sixteen (16) after years of misdiagnosis, advocated for early diagnosis, community awareness, and government support for patient ambassadors. He underscored the mortality risk among the unidentified haemophilic patient population and the urgency of reaching the 3,800 undiagnosed Kenyans.

c) Ms. Roseanne Anguche - A Clinician Representative

37. Ms. Anguche, a clinician with over twelve (12) years' experience submitted that there are systemic gaps in clinical training, noting that hemophilia care is largely absent from the medical and nursing curricula. She reported that haematologists and other doctors frequently lack sufficient knowledge to manage the condition and that a huge part of her own training was donor-funded. She called for the inclusion of haemophilia care in professional training programmes and for routine antenatal screening for bleeding disorders to be mandated to address preventable maternal mortality.

3.3 Submission by the Cabinet Secretary, Ministry of Health

38. The Cabinet Secretary for the Ministry of Health formally submitted the Ministry's response to the Petition vide a letter dated 1st April, 2026.

39. Appearing before the Committee on Tuesday, 21st April, 2026 on behalf of the Cabinet Secretary, Dr. Elias Melly, the Chief Executive Officer (CEO)-National Cancer Institute of. Kenya (NCI-K) submitted that:

40. Haemophilia is a hereditary bleeding disorder arising from a deficiency of clotting factors, resulting in prolonged bleeding episodes, increased risk of disability, and a significantly reduced quality of life for affected individuals. In Kenya, approximately 1,265 cases have been identified; however, this figure is likely an underestimation due to limited diagnostic capacity across the country. At present, diagnostic services are largely confined to Kenyatta National Hospital and Moi Teaching and Referral Hospital, while many other health facilities lack the necessary reagents and capacity to support diagnosis. Additionally, there is no structured national screening programme, awareness of the condition remains low, and many cases are diagnosed late, further compounding the burden on patients and the health system.

41. The Ministry of Health, in collaboration with the Kenya Haemophilia Association and County Governments, has established sixteen (16) treatment centres across fifteen (15) counties and eleven (11) primary care centres offering supportive services. However, access to treatment remains limited, with clotting factor concentrates (Factors VIII and IX) largely unavailable to most patients. Despite a 2023 Memorandum of Understanding with the World Federation of Haemophilia to supply factor concentrates worth approximately USD 20 million annually, donations meet only about 30% of patient needs.

42. Advanced therapies cost between USD 30,000 and USD 230,000 per patient annually, highlighting the need for sustainable financing. Due to limited factor supply, patients rely on less effective alternatives such as whole blood or cryoprecipitate, with most costs borne out-of-pocket or through charitable support. Haemophilia treatment is not currently covered under the Social Health Authority (SHA), while the Kenya Haemophilia Association continues to support advocacy and patient care. Accordingly, in order to address the foregoing challenges relating to cost, access, and sustainability of haemophilia care, the Ministry had reviewed the petition as follows:

i. Recommend the formal recognition of clotting factor concentrates as essential medicines for the treatment of haemophilia in both adults and children, and ensure their sustainable availability within the Kenyan market

43. The Ministry concurs with the recommendation to formally recognize Clotting Factor Concentrates as essential medicines for the treatment of haemophilia in both adults and children. This recommendation is timely, particularly as the Kenya Essential Medicines List (KEML) is currently under review. In this process, clotting factor concentrates and other essential haemophilia products will be formally submitted for consideration.

ii. Recommend to the Ministry of Health to establish additional haemophilia treatment centres nationwide; enhance diagnostic capacity; improve training of healthcare workers (including paediatric specialists); review medical curricula to incorporate the management of haemophilia and bleeding disorders; and increase funding for awareness, particularly for early childhood screening;

(a) Establishment of additional haemophilia treatment centres and enhancement of diagnostic capacity

44. The Ministry is implementing an integrated service delivery model as part of ongoing health system strengthening under the Universal Health Coverage (UHC) agenda. Haemophilia is a chronic condition requiring continuous, coordinated care across the life course, including early identification in childhood, preventive and therapeutic care during adolescence, and long-term management in adulthood. Accordingly, haemophilia services are already being integrated into existing platforms, including maternal and child health services, and will progressively be incorporated into other relevant programmes to ensure comprehensive, person-centred care.

45. In collaboration with county governments and Kenya Haemophilia Association, the Ministry is progressively expanding haemophilia services through a hub-and-spoke model, with comprehensive care anchored at referral hospitals and linked county facilities providing diagnosis, referral, follow-up, physiotherapy, counselling, and family education. Currently, there are two comprehensive haemophilia treatment centres and fourteen (14) other treatment centres across fifteen (15) counties, reflecting ongoing efforts to decentralize services and improve access. Further, there are eleven (11) health facilities that do not offer treatment but have been trained to offer supportive services such as physiotherapy (Annex 1).

(b)Training of healthcare workers and review of medical curricula

46. In response to the concerns raised, the Ministry has prioritized capacity building of healthcare workers through targeted training across all levels of care and cadres. The Ministry acknowledges that past trainings were made possible through collaboration with the Kenya Haemophilia Association, and remains committed to continuing this partnership to strengthen healthcare worker capacity and improve haemophilia care. It is worthy to note that the treatment guidelines developed by the Ministry have been useful in standardizing care, guiding clinical decision-making, and improving the quality and consistency of haemophilia management across healthcare facilities. The Ministry is also taking deliberate steps to ensure that community health promoters are well-equipped with the knowledge to educate the public on haemophilia and other bleeding disorders. To this end, the Ministry plans to develop a dedicated training module for CHPs to enhance community awareness and support early detection.

47. Regarding the review of the medical curriculum, the Kenya Medical Training College is in the process of reviewing its curriculum to ensure comprehensive coverage of haemophilia and other rare bleeding disorders.

48. The Ministry plans to convene consultative forums with other medical colleges and universities to encourage them to review and update their curricula, ensuring that training on haemophilia and related bleeding disorders is adequately integrated across all health professional programs.

(c) Increased Funding for Awareness and Early Screening

49. The Ministry will progressively increase budgetary allocation to support haemophilia and other non-communicable diseases, with a focus on strengthening awareness, promoting early childhood screening, and improving access to diagnostics, treatment, and comprehensive care service.

iii. Recommend the recognition of haemophilia as a disabling condition, to enable registration of both adult and paediatric patients with the National Council for Persons with Disabilities (NCPWD), and to support the inclusion of haemophilia services under the Social Health Insurance Fund (SHIF);

50. The Ministry will engage with the relevant Ministries, Departments, and Agencies (MDAs), including the National Council for Persons with Disabilities (NCPWD), to

review the proposal for recognition of haemophilia as a disabling condition, guided by the laid-out criteria.

51. The Ministry acknowledges that haemophilia care imposes a significant financial burden on households when financed through out-of-pocket payments. The Petitioner's request for inclusion of haemophilia services under the Social Health Insurance Fund (SHIF) is therefore well justified and aligned with the principles of financial risk protection under Universal Health Coverage. The Ministry together with key stakeholders will define the haemophilia benefits package for consideration by the Benefits Package and Tariffs Advisory Panel, to ensure that services are comprehensive, equitable, and financially sustainable.

iv. To make any further recommendations deemed necessary to address the challenges faced by adult and paediatric patients living with haemophilia and other bleeding disorders in Kenya

52. The Ministry recognizes that haemophilia requires a multi-dimensional and system-wide approach that extends beyond clinical treatment to include prevention, early detection, continuous care, rehabilitation, psychosocial support, and financial protection. Accordingly, the Ministry will continue to strengthen policy, programmatic, and health system interventions within the broader Non-Communicable Diseases (NCD) framework.
53. In addition to the measures outlined above, the Ministry will prioritize:

    i. Strengthening integrated service delivery across the life course, anchored in Primary Health Care and supported by effective referral systems.
    ii. Establishment of a haemophilia registry through the Digital Health Agency (DHA) to enable real-time patient tracking and data collection, supporting evidence-based decision-making.
    iii. Strengthening supply chain systems to ensure consistent availability of clotting factor concentrates and related commodities. In line with the Government's directive on pooled procurement, the Ministry will explore collaborative initiatives with relevant stakeholders, including pharmaceutical suppliers and regional procurement agencies, to enhance the efficiency, affordability, and consistent availability of clotting factor concentrates and other essential haemophilia commodities.
    iv. Promoting local and global partnerships, including collaboration with patient organizations, professional bodies, and development partners.
    v. Advancing research and evidence generation to inform policy, planning, and resource allocation for our setting.

54. The Ministry concluded by appreciating the concerns raised and reaffirms its commitment to the realization of the right to the highest attainable standard of health, as enshrined under Article 43(1)(a) of the Constitution of Kenya. Haemophilia and related bleeding disorders, though rare, constitute a significant public health concern due to their chronic nature, high cost of management, and impact on quality of life, particularly among children. The Ministry will continue to monitor implementation progress and emerging needs, and will make appropriate policy and programmatic adjustments to ensure that persons living with haemophilia and other bleeding disorders receive equitable, quality, and sustainable care.

CHAPTER FOUR

4.0 COMMITTEE OBSERVATION

55. Upon engaging the Petitioners and the Ministry of Health, the Committee made the following observations on the concerns raised by the Petitioners:

a) Kenya has an estimated 4,500 to 5,500 people living with haemophilia, but only 1,265 have been formally identified. The remaining 3,800 go undiagnosed, leading to preventable deaths and disability. Diagnostic services exist only at Kenyatta National Hospital and Moi Teaching and Referral Hospital. No national screening programme exists.

b) The World Federation of Haemophilia currently donates clotting factor concentrates worth approximately USD 20 million annually, covering only 30% of patient needs. The Memorandum of Understanding on this donation expires in early 2027. Most Kenyan haemophilia patients will lose access to life-saving treatment if sustained funding for clotting factor concentrates is not guaranteed thereafter.

c) Haemophilia treatment is not covered by the Social Health Authority even though severe cases of haemophilia treatment cost between USD 30,000 and USD 230,000 per patient annually. This level of expenditure is burdensome and catastrophic for most families with haemophilic patients. The national health insurer needs to makes provision for haemophilia treatment so as to ease the burden of the families of persons living with haemophilia.

d) There are sixteen (16) haemophilia treatment centres across fifteen (15) counties and only eleven (11) primary care centres offering supportive services. Patients therefore have to travel beyond recommended distances to receive comprehensive haemophilia care.

e) Haemophilia is not included in the medical and nursing curricula which affects effective diagnosis of the disease. Women with bleeding disorders are not routinely screened before labour which has contributed to preventable maternal deaths linked to bleeding disorders such as the Von Willebrand disease. Young undiagnosed boys are also at risk of death due to excessive bleeding during circumcision.

f) The national antenatal care framework currently does not have screening protocols for bleeding disorders and haemophilia carrier status. This may lead to postpartum haemorrhage among women with undiagnosed bleeding disorders.

g) A large part of clinical training on haemophilia management is donor funded and the continuity of such training will become uncertain with the impending expiry of the Memorandum of Understanding with the World Federation of Haemophilia in early 2027.

h) Haemophilia is not classified as a disabling condition in Kenya and as such haemophilia patients do not have access to the benefits and protections under the Persons with Disabilities Act, 2025. Psychosocial support is not well provided within the national health system to haemophilia patients and their caregivers who sometimes experience job loss, family breakdown and extended periods of non-attendance of school in the case of haemophilic children.

i) The country does not have a national patient registry on persons living with haemophilia which leads to data fragmentation which further prevents evidence-based planning and policy making on matters relating to the management of haemophilia patients.

j) A similar Petition (Public Petition No. 60 of 2019 regarding the management of Hemophilia and other bleeding disorders among patients in Kenya dated 20th June, 2019) was previously submitted to the National Assembly on 26th June, 2019 by Hon. David Ole Sankok, MP on behalf of Hemophilia Patients of Kenya. The same was considered by the then Committee and a report tabled on 9th October 2029 presented in the National Assembly. The report had several recommendations, which have not yet been implemented, including that:

   (i) The National Treasury should put in place a mechanism to automatically waive Railway Development Levy (RDL) and Import Declaration Fees (IDF) related to treatment of hemophilia including clotting factor concentrates and any other -donated drugs related to treatment of hemophilia;
   (ii) The relevant regulations related to classification of essential drugs should be amended to include provision on treatment of bleeding disorders including hemophilia;
   (iii) The relevant tax legislations should be amended to exempt donated drugs;
   (iv) Hemophilia should be recognized as a disabling condition by the National Council of Persons with Disability and the condition should be covered by the National Hospital Insurance Fund; and
   (v) The Ministry of Health in collaboration with County Governments should embark on public awareness campaign on bleeding disorders including hemophilia.

CHAPTER FIVE

5.0 COMMITTEE RECOMMENDATIONS

56. Pursuant to the Provisions of Standing Order 227, the Committee recommends as follows in response to the Petitioners' prayers:

a) That the Cabinet Secretary, Ministry of Health includes clotting factor concentrates (Factors VIII, IX, and XI) covering both adult and paediatric formulations as essential medicines in the Kenya Essential Medicines List (KEML).

b) The Ministry of Health, the Kenya Medical Supplies Authority and the County Governments ensures sustainable procurement and consistent distribution and availability of clotting factor concentrates (Factors VIII, IX, and XI) within the national supply chain including through pooled procurement arrangements with local, regional and international agencies.

c) That the Cabinet Secretary, Ministry of Health, the Social Health Authority and the Benefits Package and Tariffs Advisory Panel to develop comprehensive haemophilia benefits packages under the Primary Health Care Fund, the Social Health Insurance Fund and the Emergency, Chronic and Critical Illness Fund that make provision for clotting factor infusions, specialist consultations, hospital admissions, physiotherapy, diagnostics and screening, and psychosocial support; and reports to the House within six months upon tabling of this report on the details of the packages developed.

d) That the Ministry of Health and the National Board for Social Protection recognizes haemophilia patients and their caregivers as vulnerable persons and affords them the necessary social assistance and social care pursuant to the provisions of the Social Protection Act, No. 12 of 2025; and reports to the House within one year upon the tabling of this report on the type of social assistance provided to haemophilia patients and their caregivers.

e) That the Ministry of Health, in collaboration with the National Council for Persons with Disabilities, classifies haemophilia as a disabling condition to afford haemophilia patients access to the benefits and protections availed to all persons living with disabilities under the Persons with Disabilities Act, 2025 and any other written law.

f) That the Ministry of Health, in collaboration with the County Governments, establishes additional fully-fledged haemophilia treatment centres with trained clinical staff, diagnostic capacity, reliable access to clotting factor concentrates and physiotherapy services in all underserved counties.

g) That the Ministry of Health, Ministry of Education, Healthcare Professional Statutory Regulatory Bodies and the Kenya Medical Training College incorporates haemophilia management in the clinical training and education curricula.

h) That the Ministry of Health and the County Governments regularly trains Community Health Promoters and Community Health Officers and Assistants on early identification and referral of bleeding disorders.

i) That the Digital Health Agency introduces a national haemophilia registry under the Comprehensive Integrated Health Information System established and maintained under section 15 of the Digital Health Act, No. 15 of 2023 to enable real-time patient tracking and evidence-based decision making and planning in relation to haemophilia care and management; and reports to the House within four months upon tabling of this report on the deployment and use of the registry.

j) That the Ministry of Health undertakes national awareness on bleeding disorders including haemophilia; and reports to the Committee within six months upon tabling of this report on the details of the national awareness programmes undertaken.

k) That pursuant to the provisions of Standing Order 208A(2)(c), the findings arising from the consideration of this Petition be debated by the House.

SIGNED..... **DATE**...22/6/2026.....

HON. DR. JAMES NYIKAL WAMBURA, CBS, M.P.
CHAIRPERSON, DEPARTMENTAL COMMITTEE ON HEALTH

THE NATIONAL ASSEMBLY
PAPERS LAID

DATE: 23 JUN 2026	DAY. TUESDAY
TABLED BY:	Hon Dr. James Nyikal MP CHAIR, DC HEALTH
CLERK-AT THE-TABLE:	P Mulya.