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9/10/19

THE NATIONAL ASSEMBLY



TWELFTH PARLIAMENT (THIRD SESSION)

DEPARTMENTAL COMMITTEE ON HEALTH

REPORT ON THE

PUBLIC PETITION (No. 60 OF 2019) REGARDING MANAGEMENT OF HEMOPHILIA
AND OTHER BLEEDING DISORDERS AMONG PATIENTS IN KENYA

CLERKS CHAMBERS
DIRECTORATE OF COMMITTEE SERVICES
PARLIAMENT BUILDINGS
NAIROBI

OCTOBER, 2019

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ABBREVIATIONS

FY	Financial Year
IDF	Import Declaration Fees
KEMSA	Kenya Medical Supplies Authority
KNH	Kenyatta National Hospital
HCCC	Hemophilia Comprehensive Care Clinics
MTRH	Moi Teaching and Referral Hospital
MOU	Memorandum of Understanding
NHIF	National Hospital Insurance Fund
RDL	Railway Development Levy
SAGAs	Semi-Autonomous Government Agencies
UHC	Universal Health Coverage

CHAIRPERSON'S FOREWORD

The Public Petition No. 60 of 2019 regarding the management of Hemophilia and other bleeding disorders among patients in Kenya, dated 20th June, 2019 was presented in the National Assembly on 26th June, 2019 by Hon. David Ole Sankok, MP on behalf of Hemophilia Patients of Kenya. The Petition was subsequently committed to the Departmental Committee on Health for consideration pursuant to Standing Order 227(1).

The Committee was required to respond to the Petitioner by way of a report addressed to the Petitioner and laid on the Table of the National Assembly not more than sixty (60) calendar days from the time of reading the Petition.

In processing the Petition, the Committee received views from the Ministry of Health and the Petitioner, the Hon. David Ole Sankok, MP accompanied by Dr. Kibet P. Shikuku, Lecturer at the University of Nairobi, Department of Hematology and Blood Transfusion and Mr. James Kago, a hemophilia patient. The Committee analyzed their submissions and prepared the report.

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. Finally, I wish to express my appreciation to the Honorable Members of the Committee and all those who made useful contributions towards the preparation and production of this report.

On behalf of the Departmental Committee on Health and pursuant to provisions of Standing Order 227(2), it is my pleasant privilege and honour to present to this House the report of the Committee on its consideration of the Public Petition No. 60 of 2019 regarding management of Hemophilia and other bleeding disorders among patients in Kenya.

Hon. Sabina Chege, MP

EXECUTIVE SUMMARY

The Committee in responding to the Petitions prayers, sought views from the Ministry of Health and held a meeting with the Petitioner, the Hon. David Ole Sankok, MP accompanied by Dr. Kibet P. Shikikuku, Lecturer at the University of Nairobi, Department of Haematology and Blood Transfusion, and Mr. James Kago, a hemophilia patient.

The Petitioner said that hemophiliacs suffer substantially reduced quality of life due to this life-threatening condition. Hemophilia is a relatively rare disorder and its prevalence stood at 1 out of 10,000 individuals, with approximately 5,000 affected in Kenya. The Association of Hemophilia Patients in Kenya had managed to reach only 700 of them.

The disease is congenital but could also be acquired. Hemophiliacs lack some protein mediated through the X-chromosome which affects the clotting of blood, leaving patients with the risk of bleeding to death. The disease mainly affects males.

The medication for the disease in Kenya is expensive, at about Kshs. 30 per unit, with a patient needing about 3,500 units per single course of treatment. Patients in Kenya, therefore, depend majorly on donations from international donors. However, the donors face challenges of clearance of these donations by the relevant tax collecting agency, who demands Import Declaration Fees (IDF) and Railway Development Levy (RDL) on donated drugs.

The Committee recommends that 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.

The relevant regulations related to classification of essential drugs should be amended to include provision on treatment of bleeding disorders including hemophilia. Further, relevant tax legislations should be amended to exempt donated drugs.

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, among other recommendations detailed in this report.

1.0 PREFACE

1.1 Establishment of the Committee

1. The Departmental Committee on Health is established pursuant to the provisions of Standing Order No. 216 of the National Assembly and in line with Article 124 of the Constitution which provides for the establishment of the Committees by Parliament. The mandate and functions of the Committee are;
 - a) *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) *Study the programme and policy objectives of the Ministries and departments and the effectiveness of the implementation;*
 - c) *Study and review all legislation referred to it;*
 - d) *Study, assess and analyze the relative success of the Ministries and departments as measured by the results obtained as compared with its stated objectives;*
 - e) *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;*
 - f) *Vet and report on all appointments where the constitution or any law requires the National Assembly to approve, except those under Standing Order 204;*
 - fa) *Examine treaties, agreements and conventions;*
 - g) *Make reports and recommendations to the House as often as possible, including recommendation of proposed legislation;*
 - h) *Consider reports of Commissions and Independent Offices submitted to the House pursuant to the provisions of Article 254 of the Constitution; and*
 - i) *Examine any questions raised by Members on a matter within its mandate.*

1.2 Mandate of 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.
3. The Departmental Committee is mandated to cover the functions of the Ministry of Health alongside Semi-Autonomous Government Agencies (SAGAs) including but not limited to; Kenyatta National Hospital; Moi Teaching and Referral Hospital; Kenya Medical Training College; Kenyatta University Teaching and Referral Hospital; Kenya Medical Supplies Authority and National Hospital Insurance Fund.

1.3 Committee Membership

4. The Departmental Committee on Health was constituted by the House in December, 2017 and comprises of the following Members:-

Hon. Sabina Chege, MP (**Chairperson**)
County MP for Muranga County
Jubilee Party

Hon. Dr. Swarup Ranjan Mishra, MP (**Vice-Chairperson**)
M.P for Kesses Constituency
Jubilee Party

Hon. (Dr.) James Nyikal, MP for Seme Constituency
ODM Party

Hon. (Dr.) Eseli Simiyu, MP MP for Tongaren Constituency
FORD-K

Hon. (Dr.) James K. Murgor, MP for Keiyo North Constituency
Jubilee Party

Hon. Muriuki Njagagua, MP for Mbeere North Constituency
Jubilee Party

Hon. (Dr.) Mohamed D. Duale, MP for Daadab Constituency
KANU Party

Hon. Alfred Agoi Masadia, MP for Sabatia Constituency
ANC Party

Hon. Stephen Mule, MP for Matungulu Constituency
WIPER Party

Hon. David Ochieng', MP for Ugenya Constituency
MDG Party

Hon. Esther M. Passaris, MP for Nairobi County
ODM Party

Hon. Gladwell J. Cheruiyot, MP for Baringo County
KANU Party

Hon. Kipsengeret Koros, MP for Sigowet Constituency
Independent Member

Hon. Martin Peters Owino, MP for Ndhiwa Constituency
ODM Party

Hon. Mercy Wanjiku Gakuya, MP for Kasarani Constituency
Jubilee Party

Hon. Prof. Mohamud S. Mohamed, MP for Alego Usonga Constituency
Jubilee Party

Hon. Patrick Munene Ntwiga, MP for ChukaIgamba Ng'ombe Constituency
Jubilee Party

Hon. Tongoyo Gabriel Koshal, MP for Narok West Constituency
CCM Party

Hon. Zachary Kwenya Thuku, MP for Kinangop Constituency
Jubilee Party

1.4 Committee Secretariat

5. The Committee is facilitated by the following technical staff:-

Mr Benjamin Magut
First Clerk Assistant/Lead Clerk

Mr. Ahmed Hassan Odhwa
Principal Research Officer

Mr. Muyodi Meldaki Emmanuel
Clerk Assistant III

Mr. Eric Kanyi
Fiscal Analyst I

Ms. Lynette A. Otieno
Legal Counsel I

Ms. Winnie Kiziah
Media Officer

1.5 Committee Recommendation


6. As per the Petitioner's prayers, the Committee recommends that:

1. The Ministry of Health should implement the commitments highlighted in paragraph 22,23, 24,25,26,27,28 of their submissions to the Committee and report to the National Assembly within six months of tabling of this report on the Floor of the House on the status of implementation, that is-
 - i. Budget for the essential factors and other lifesaving medications in this financial year that is FY2019/2020 before the expiration of the Memorandum of Understanding (MOU) between the Kenyan Government and the World Federation of Hemophilia that is scheduled to end in 2021.
 - ii. Use the existing purchase and distribution mechanism, Kenya Medical Supplies Authority (KEMSA), to ensure all patients receive factor concentrate donations at their nearest health facilities.
 - iii. Conduct an aggressive market survey through the Pharmacy and Poisons Board on the availability of advanced pharmaceutical therapies in the market for the management of hemophilia. The Board should also provide support to manufacturers in registration of the products related to treatment of hemophilia.
 - iv. Establishment of more Hemophilia treatment centers in "hot spots" areas in collaboration with County governments and other stakeholders (Kenya Hemophilia Association).

- v. Develop adequate capacity for diagnosis and monitoring of patients at Kenyatta National Hospital (KNH) and Moi Teaching and Referral Hospital (MTRH) and extend it to Coast Provincial General Hospital, Muranga and Kisii County Referral Hospitals. The said counties (Nairobi, Uasin Gishu County, Mombasa, Muranga and Kisii) and others should be included in the treatment portfolio and be capacitated to provide diagnostic tests. Further, ensure that sustainability of the reagents for testing will be a function of the county governments as Universal Health Coverage (UHC) is being rolled out.
 - vi. The development of disability guidelines which would include all the genetically inherited diseases such as hemophilia.
 - vii. The full implementation of Universal Health Coverage (UHC) which should ensure the efficient treatment of hemophilia.
2. The National Treasury should put in place a mechanism to automatically waive Railway Development Levy (RDL) and Import Declaration (IDF) Fees related to treatment of hemophilia including clotting factor concentrates and any other donated drugs related to treatment of hemophilia.
 3. The relevant regulations related to classification of essential drugs should be amended to include provision on treatment of bleeding disorders including hemophilia. Further, relevant tax legislations should be amended to exempt donated drugs.
 4. 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.
 5. The Ministry of Health in collaboration with County Governments should embark on public awareness campaign on bleeding disorders including hemophilia.

1.6 Acknowledgement

7. The Committee appreciates the assistance provided by the Office of the Speaker and the Clerk of the National Assembly that enabled it to discharge its functions in considering the Petition.
8. On behalf of the Committee, and pursuant to Standing Order, 227 it is my duty to table in the House the Report of the Committee on the Petition.

Signed.......... Date.....8/10/19.....
Hon. Sabina Chege, MP
Chairperson, Departmental Committee on Health

CHAPTER ONE

2 INTRODUCTION

2.0 BACKGROUND

9. The Public Petition No. 60 of 2019 regarding the management of Hemophilia and other bleeding disorders among patients in Kenya, dated 20th June 2019 was presented in the National Assembly on 26th June 2019 by Hon. David Ole Sankok, MP on behalf of Hemophilia Patients of Kenya.
10. Hon. David Ole Sankok, MP was accompanied by Dr. Kibet P. Shikuku, Lecturer at the University of Nairobi, Department of Haematology and Blood Transfusion, and Mr. James Kago, a hemophilia patient, who in their interaction with the Committee made written and oral submissions.
11. The Petitioner said that hemophiliacs suffer substantially reduced quality of life on account of frequent life-threatening bleeding episodes. Hemophilia is a relatively rare disorder and its prevalence has been computed in Kenya and it stands at 1 out of 10,000 individuals, with approximately 5,000 affected. The Association of Hemophilia patients in Kenya had managed to reach only 700 of them.
12. The disease is congenital but could also be acquired. Hemophiliacs lack some protein mediated through X-chromosome which affects the clotting of blood, leaving patients with the risk of bleeding to death. The disease mainly affects males.
13. The medication for the disease in Kenya is expensive, at about Kshs. 30 per unit, with a patient needing about 3,500 units per single episode of treatment. Patients in Kenya, therefore, depend majorly on donations from international donors. However, the donors face challenges of clearance of these donations by relevant tax collection agency, who demand Import Declaration Fees (IDF) and Railway Development Levy (RDL) on donated drugs.
14. In light of the above, the Petitioners pray that the National Assembly, through the Departmental Committee on Health considers the matters raised in the Petition pursuant to the provisions of Standing orders 227 and make recommendations thereof.

2.1 PETITIONERS PRAYERS TO THE NATIONAL ASSEMBLY

15. The Petitioner prayed that the National Assembly through the Departmental Committee on Health:
 - i) Recommends the recognition of clotting factor concentrates as part of hemophilia's treatment and facilitates their availability in the Kenyan market;
 - ii) Recommends to the Ministry of Health the establishment of more treatment centers, the improvement of diagnostic capacity, the facilitation of training of health care workers, the review of medical-training curriculum to include hemophilia and other bleeding disorders management and care in all medical training institutions, and funding support to aid in creation and facilitation to hemophilia disease awareness;

- iii) Recommends the recognition of hemophilia as a disabling condition to enable the recognition of hemophilia patients with the National Council of Persons with Disability and support the coverage of the condition by the NHIF.

2.2 LEGAL PROVISIONS TOUCHING ON THE PETITION

2.2.1 RIGHT TO PETITION PARLIAMENT

15. The right to Petition Parliament is provided for under Article 119 of the Constitution, which provides as follows:-

“Every person has a right to Petition Parliament to consider any matter within its authority, including enacting, amending or repealing any legislation. Parliament shall make provision for the procedure for the exercise of this right.”

16. The Petition, therefore falls under the Committee's mandate under National Assembly Standing Order 227(1). In addition, Standing Order 227(2) outlines the procedure for committal of a Petition to a Committee and transmission of its decision to the Petitioner. Further, the Petitions to Parliament (Procedure) Act, 2012 provides for the procedure to be followed in the submission, processing and consideration of a Petition.

Article 94 as read together with Article 95 of the Constitution further provides for the mandate of Parliament and the National Assembly respectively. Generally, the Houses of Parliament exercise the legislative mandate of the people, deliberate on matters of national interest and oversight the exercise of power by other arms of government.

17. Public participation is now a guaranteed process in Kenya. The Constitution in various Articles requires that public participation be undertaken at all levels of government before government officials make decision affecting the public.
18. Public participation is having an open, accountable and structured process where citizens or people, or a segment of a community can interact, exchange views and influence decision making. Public participation is part of a democratic process.

CHAPTER TWO

3.0 SUBMISSIONS ON THE PETITION

3.1 PETITION BY HON. DAVID OLE SANKOK, MP

20. While appearing before the Committee on 17th September 2019 the Hon. David Ole Sankok, MP, accompanied by Dr. Kibet P. Shikuku, Lecturer at the University of Nairobi, Department of Haematology and Blood Transfusion and Mr. James Kago a hemophilia patient on behalf of the Hemophilia Patients of Kenya submitted, That;

- i) The right to health is a fundamental human right guaranteed in the Constitution of Kenya, with Article 43(1)(a) stipulating that every person has the right to the highest attainable standard of health including the right to health care services;
- ii) Patients with Hemophilia suffered substantially reduced quality of life on account of frequent bleeding episodes and disorders most of which were life-threatening or lead to disabling joint disease (arthropathy) and shortened life expectancy;
- iii) Methods of treatment and management of hemophilia were costly and typically time-consuming, and thus end up placing a considerable burden on patients' physical, financial and psychological well-being;
- iv) The only treatment product recognized by the Ministry of Health in its Essential Drugs List was blood components, which meant that the Kenya Medical Supplies Authority (KEMSA) could not purchase the appropriate drugs to be used locally and even pharmaceuticals dealing in clotting factor concentrates could not conveniently import the medicine into the Country;
- v) The prevalence of Hemophilia is 1 in every 10,000 individuals, and out of the approximately 5,000 hemophilia patients in Kenya, only 700 patients (or 16% of the total) had been identified, hence the need for sustained awareness of the condition;
- vi) The clotting factor concentrate donations received at present were insufficient and inconsistent, giving 30% factor level for the 700 (16%) patients that had so far been identified and thus at times forcing patients to revert to blood-related products that required hospital admission for transfusion;
- vii) The current donation program that purchases clotting factor concentrates for the patients is only able to cater for 30% for the Factor concentrates and the program is scheduled to end in 2021.
- viii) There are currently only three fully operational Hemophilia treatment centers (Moi Teaching and Referral, Coast General and Kenyatta National hospital) in the country in the face of the need to make treatment and care available in all referral hospitals and facilitates which should have

testing and diagnosis machines that could undertake basic coagulation tests besides supporting treatment including physiotherapy;

- ix) There is limited knowledge about the condition amongst health care providers hence complicating their ability to diagnose and appropriately refer patients to established facilities;
- x) Efforts to sufficiently address the plight of hemophilia patients had not borne much fruit; and
- xi) The issues in respect of which this Petition was made were not pending before any Court of Law or any Constitutional or Statutory body.
- xii) Dr. Kibet P. Shikuku, Lecturer at the University of Nairobi, Department of Haematology and Blood Transfusion added that hemophilia was congenital but could also be acquired. Patients lacked some protein mediated through X-chromosome which affected the clotting of blood, leaving patients with the risk of bleeding to death. The disease mainly affected males.
- xiii) Prevalence stands at 1 out of 10,000 individuals, with approximately 5,000 affected. The Association of Hemophilia patients in Kenya had managed to reach only 700 of them.
- xiv) Necessary drugs had not been classified by the Ministry of Health in its essential drugs list and were thus not procured by KEMSA. The medication is expensive, at about Kshs. 30 per unit, with a patient needing about 3,500 units per single episode treatment. Local patients, therefore, depended majorly on donations from an international donor. However, the donor faced challenges of clearance of these donations by the relevant tax collection agencies that impose Import Declaration Fees (IDF) and Railway Development Levy (RDL).
- xv) He added that the hemophilia patients were at risk now that the country was losing donor support progressively.
- xvi) Mr. James Kago, a hemophilia patient called for availability of all factor concentrates for better management of the disease in the country and that the medical profession and the public should also be informed extensively about the condition.

3.2 SUBMISSIONS BY THE CABINET SECRETARY, MINISTRY OF HEALTH

Appearing before the Committee on 17th September 2019 on behalf of the Cabinet Secretary, Ms. Susan Mochahe, Principal Secretary, Ministry of Health submitted that;

- 21. The clotting factor concentrates are recognized as part of the Ministry of Health Hemophilia Treatment Guidelines. Hemophilia and other bleeding disorder patients had been receiving care through donated clotting factor concentrates from the World Federation of Hemophilia through a memorandum of understanding (MOU signed in November 2016 and ends in 2021) between the Kenyan Government and the Federation. However, the availability of factor concentrates had faced challenges of providing the same in the Health facilities leading to erratic supply.
- 22. The Government through the Ministry of Health will budget for the essential factors and other lifesaving medications before the expiration of the MOU. It will also consider patients who require specialized products which are equally expensive.

23. The Ministry was receiving factor concentrate donations and distributing through Kenyatta National Hospital (KNH) to 3 treatment facilities nationally. It would use the existing purchase and distribution mechanism Kenya Medical Supplies Authority (KEMSA) to ensure all patients receive products at the nearest health facility.
24. The Ministry through the Pharmacy and Poisons Board will conduct an aggressive market survey on the available advanced pharmaceutical therapies in the market for the management of hemophilia. To enhance the smooth availability of drugs for this condition the Board will provide support to manufacturers during the registration of their products.
25. The Ministry has also been collaborating with the County governments and other stakeholders (Kenya Hemophilia Association) in establishing treatment centers in "hot spots" while developing Kenyatta National Hospital (KNH) and Moi Teaching and Referral (MTRH) as Hemophilia Comprehensive Care Clinics (HCCC). More centers would be established once products are made readily available.
26. The Ministry had developed adequate capacity for diagnosis and monitoring of patients at KNH and MTRH, this was being extended to Coast Provincial General Hospital, Muranga and Kisii County Referral Hospitals. These counties and others that would be included in the treatment portfolio will be capacitated to provide diagnostic tests. The sustainability of the reagents for testing will be a function of the county governments as Universal Health Coverage (UHC) was being rolled out. Ministry of Health will continue to provide policy direction on testing.
27. Health care professionals are being trained on care of various types of diseases including hemophilia and other bleeding disorders. The Ministry was also developing the disability guidelines which would include all the genetically inherited disease conditions like hemophilia.
28. Hemophilia is being managed through the existing NHIF scheme done through an integrated disease management approach. The patients with hemophilia would greatly benefit from the full operationalization of Universal Health Coverage (UHC).

CHAPTER THREE

4.0 COMMITTEE OBSERVATIONS

29. Arising from the submissions, The Committee observed that;

- i) Prevalence of Hemophilia in Kenya is 1 in every 10,000 individuals, and out of the approximately 5000 hemophilia patients in Kenya, only 700 patients (or 16% of the total) have been identified.
- ii) Hemophiliacs face several challenges, including the high cost of clotting factor products. The medication is expensive, at about Kshs. 30 per unit, with a patient needing about 3,500 units per treatment episode. Local patients, therefore, depend majorly on donations from international donors.
- iii) The donors face challenges of clearance of these donations by customs at the ports, where Import Declaration Fees (IDF) and Railway Development Levy (RDL) are imposed on donated drugs.
- iv) Only three (3) hospitals in Kenya run hemophilia comprehensive care clinics: Moi Teaching and Referral, Coast Provincial General Hospital and Kenyatta National Hospital.
- v) Lack of awareness concerning the condition among the patients, health-care practitioners, and the general public remains a barrier in the management of hemophilia. The majority don't have familial history of hemophilia hence many cases go undetected and patients miss opportunities for early therapy.
- vi) The cost and burden of the disease are particularly higher for patients who live in rural areas due to distance to the health care center, higher levels of poverty, lack of proper means of transportation and out-of-pocket costs making many to forgo treatment.
- vii) Hemophiliacs suffer substantially in almost all aspects of their lives. For example, the social life of a school going child comes with potentially grave consequences if the child engages in risky activities particularly sports with their peers.
- viii) Donations of clotting factor concentrates on Hemophilia and other bleeding disorder patients is courtesy of Memorandum of Understanding (MOU) between the Kenyan government and the World Federation of Hemophilia (signed in November 2016 and ends in 2021). However, the program is only able to cater for 30% for the Factor concentrates and the program is scheduled to end in 2021.
- ix) Factor concentrates is one of the pillars for a successful management of severe and moderate hemophilia. However, non-availability of especially Factor 8 or 9 in the country is the major inhibitor to the proper management of the disease.
- x) The only treatment product currently recognized by the Ministry of Health in its Essential Drugs List is blood components, which means that the Kenya Medical Supplies Authority (KEMSA) cannot purchase the appropriate drugs to be used locally and even pharmaceuticals dealing in clotting factor concentrates cannot conveniently import the medicine into the Country.
- xi) The Ministry is aware of the challenges facing bleeding disorder patients particularly hemophilia patient and is willing to factor their treatment in the budget for the FY 2020-2021.

5.0 COMMITTEE RECOMMENDATIONS


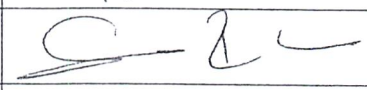


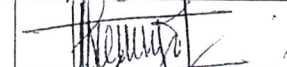


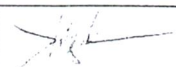
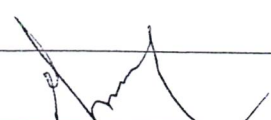
30. As per the Petitioners prayers, the Committee recommends that:

1. The Ministry of Health should implement the commitments highlighted in paragraph 22,23, 24,25,26,27,28 of their submissions to the Committee and report to the National Assembly within six months of tabling of this report on the Floor of the House on the status of implementation that is-
 - i. Budget for the essential factors and other lifesaving medications in this financial year that is FY2019/2020 before the expiration of the Memorandum of Understanding (MOU) between the Kenyan Government and the World Federation of Hemophilia that is scheduled to end in 2021.
 - ii. Use the existing purchase and distribution mechanism, Kenya Medical Supplies Authority (KEMSA), to ensure all patients receive factor concentrate donations at their nearest health facilities.
 - iii. Conduct an aggressive market survey through the Pharmacy and Poisons Board on the availability of advanced pharmaceutical therapies in the market for the management of hemophilia. The Board should also provide support to manufacturers in registration of the products related to treatment of hemophilia.
 - iv. Establishment of more Hemophilia treatment centers in "hot spots" areas in collaboration with County governments and other stakeholders (Kenya Hemophilia Association).
 - v. Develop adequate capacity for diagnosis and monitoring of patients at Kenyatta National Hospital (KNH) and Moi Teaching and Referral Hospital (MTRH) and extend it to Coast Provincial General Hospital, Muranga and Kisii County Referral Hospitals. The said counties (Nairobi, Uasin Gishu County, Mombasa, Muranga and Kisii) and others should be included in the treatment portfolio and be capacitated to provide diagnostic tests. Further, ensure that sustainability of the reagents for testing will be a function of the county governments as Universal Health Coverage (UHC) is being rolled out.
 - vi. The development of disability guidelines which would include all the genetically inherited disease conditions like hemophilia.
 - vii. The full implementation of Universal Health Coverage (UHC) which should ensure the efficient treatment of hemophilia.
2. The National Treasury should put in place a mechanism to automatically waive Railway Development Levy (RDL) and Import Declaration (IDF) Fees related to treatment of hemophilia including clotting factor concentrates and any other donated drugs related to treatment of hemophilia.
3. The relevant regulations related to classification of essential drugs should be amended to include provision on treatment of bleeding disorders including hemophilia. Further, relevant tax legislations should be amended to exempt donated drugs.
4. 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.
5. The Ministry of Health in collaboration with County Governments should embark on public awareness campaign on bleeding disorders including hemophilia.

THE NATIONAL ASSEMBLY

DEPARTMENTAL COMMITTEE ON HEALTH
ADOPTION LIST

REPORT ON THE
PUBLIC PETITION (No. 60 OF 2019) REGARDING MANAGEMENT OF HEMOPHILIA AND
OTHER BLEEDING DISORDERS AMONG PATIENTS IN KENYA
DATE: 3/10/2019 VENUE: 9TH FLOOR, HARAMBEE PLAZA, SMALL BOARDROOM
TIME 11.30AM

	NAME	SIGNATURE
1.	Hon. Sabina Chege, MP – Chairperson	
2.	Hon. Swarup Ranjan Mishra, MP – Vice-Chairperson	
3.	Hon. (Dr.) Eseli Simiyu, MP	
4.	Hon. (Dr.) James Nyikal, MP	
5.	Hon. Alfred Agoi Masadia, MP	
6.	Hon. (Dr.) James Kipkosgei Murgor, MP	
7.	Hon. Muriuki Njagagua, MP	
8.	Hon. (Dr.) Mohamed Dahir Duale, MP	
9.	Hon. Stephen Mule, MP	
10.	Hon. David Ochieng', MP	
11.	Hon. Esther M. Passaris, MP	
12.	Hon. Gladwell Jesire Cheruiyot, MP	
13.	Hon. Kipsengeret Koros, MP	
14.	Hon. Martin Peters Owino, MP	
15.	Hon. Mercy Wanjiku Gakuya, MP	
16.	Hon. Prof. Mohamud Sheikh Mohamed, MP	
17.	Hon. Patrick Munene Ntwiga, MP	
18.	Hon. Tongoyo Gabriel Koshal, MP	
19.	Hon. Zachary Kwenya Thuku, MP	

MINUTES OF THE FOURTY FIRST (41ST) SITTING OF THE DEPARTMENTAL COMMITTEE ON HEALTH HELD IN 9TH FLOOR, HARAMBEE PLAZA, SMALL BOARDROOM ON THURSDAY 3RD OCTOBER, 2019 AT 10.00 A.M.

PRESENT

1. Hon. Sabina Chege , MP - **Chairperson**
2. Hon. (Dr.) Swarup Ranjan Mishra, MP – **Vice Chairperson**
3. Hon. (Dr.) James Nyikal, MP
4. Hon. Esther M. Passaris, MP
5. Hon. Gladwell Jesire Cheruiyot, MP
6. Hon. Kipsengeret Koros, MP
7. Hon. Martin Peters Owino, MP
8. Hon. Prof. Mohamud Sheikh Mohamed, MP
9. Hon. Zachary Kwenya Thuku, MP

ABSENT WITH APOLOGY

1. Hon. (Dr.) Eseli Simiyu, MP
2. Hon. (Dr.) James Kipkosgei Murgor, MP
3. Hon. David Ochieng' MP
4. Hon. (Dr.) Mohamed Dahir Duale, MP
5. Hon. Stephen Mule, MP
6. Hon. Muriuki Njagagua, MP
7. Hon. Tongoyo Gabriel Koshal, MP
8. Hon. Mercy Wanjiku Gakuya, MP
9. Hon. Alfred Agoi Masadia, MP
10. Hon. Patrick Munene Ntwiga, MP

IN ATTENDANCE

NATIONAL ASSEMBLY SECRETARIAT

- | | | |
|------------------------|---|---------------------|
| 1. Mr. Muyodi Emmanuel | - | Clerk Assistant III |
| 2. Ms. Lynette Atieno | - | Legal Counsel I |
| 3. Ms. Rahab Chepkilim | - | Audio Officer |

MIN. NO.NA/C.H/2019/93:

PRELIMINARIES

Vice-Chairperson called the meeting to order at 10.15 am and said a prayer.

MIN. NO. NA/DC.H/2019/94:

ADOPTION OF AGENDA

The agenda of the meeting was adopted as hereunder after being proposed by Hon. (Dr.) James Nyikal, MP and seconded by Hon. Kipsengeret Koros, MP.

AGENDA

1. Prayers
2. Adoption of the Agenda
3. Confirmation of the Minutes

4. Substantive Agenda:

Adoption of the Report on the Petition (No. 60 of 2019) regarding management of Hemophilia and other bleeding disorders among patients in Kenya.

5. Any Other Business

6. Date of the Next sitting

MIN. NO.NA/DC.H/2019/95:

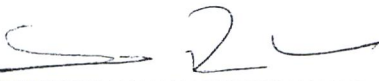
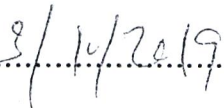
ADOPTION OF REPORT ON THE
PETITION (NO. 60 OF 2019) REGARDING
MANAGEMENT OF HEMOPHILIA AND
OTHER BLEEDING DISORDERS AMONG
PATIENTS IN KENYA.

The report was unanimously adopted after having been proposed by Hon. (Dr.) James Nyikal, MP and seconded by Hon. Martin Peters Owino, MP and signed by the Chairman.

MIN. NO.NA/DC.H/2019/96:

ADJOURNMENT

There being no other business, the meeting adjourned at 11.55 am.

Sign.......... Date..........

(Chairperson)

MINUTES OF THE THIRTY EIGHTH (37TH) SITTING OF THE DEPARTMENTAL COMMITTEE ON HEALTH HELD IN BOARD ROOM, COUNTY HALL, GROUND FLOOR, PARLIAMENT BUILDINGS ON TUESDAY 17TH SEPTEMBER 2019 AT 10.00 A.M.

PRESENT

1. Hon. Martin Peters Owino, MP – Chairing
2. Hon. (Dr.) Eseli Simiyu, MP
3. Hon. (Dr.) James Nyikal, MP
4. Hon. (Dr.) James Kipkosgei Murgor, MP
5. Hon. Stephen Mule, MP
6. Hon. Muriuki Njagagua, MP
7. Hon. Prof. Mohamud Sheikh Mohamed, MP
8. Hon. Gladwell Jesire Cheruiyot, MP
9. Hon. David Ochieng' MP
10. Hon. Tongoyo Gabriel Koshal, MP

ABSENT WITH APOLOGY

1. Hon. Sabina Chege , MP - Chairperson
2. Hon. (Dr.) Swarup Ranjan Mishra, MP – Vice Chairperson
3. Hon. (Dr.) Mohamed Dahir Duale, MP
4. Hon. Zachary Kwenya Thuku, MP
5. Hon. Kipsengeret Koros, MP
6. Hon. Mercy Wanjiku Gakuya, MP
7. Hon. Esther M. Passaris, MP

ABSENT

1. Hon. Alfred Agoi Masadia, MP
2. Hon. Patrick Munene Ntwiga, MP

IN ATTENDANCE

NATIONAL ASSEMBLY SECRETARIAT

- | | | |
|------------------------|---|-------------------------|
| 1. Mr. Benjamin Magut | - | Clerk Assistant I |
| 2. Mr. Muyodi Emmanuel | - | Clerk Assistant III |
| 3. Ms. Lynette Atieno | - | Legal Counsel I |
| 4. Ms. Winfred Kizia | - | Media Relations Officer |

MINISTRY OF HEALTH

- | | | |
|-----------------------|---|---------------------------------------|
| 1. Ms. Susan Mochache | - | Principal Secretary |
| 2. Dr. Fridah Govedi | - | Head National Blood Transfusion |
| 3. Dr. Simon Njuguna | - | Head Division of Mental Health |
| 4. Dr. Fred M. Siyoi | - | C.E.O Pharmacy and Poisons Board |
| 5. Mr. Ibrahim Abdi | - | Undersecretary/ Parliamentary Liaison |

PETITIONERS

1. Hon. David Ole Sankok, MP
2. Dr. Kibet Shikuku
3. Mr. James Kago

MIN. NO.NA/C.H/2019/72

PRELIMINARIES

In the immediate absence of the Chairperson and Vice Chairperson, Members present elected Hon. Martin Peters Owino, MP to chair the meeting, pursuant to Standing Order No. 188. Hon. Owino called the meeting to order at 10.15 am and said a prayer, followed by a round of introductions.

MIN. NO. NA/DC.H/2019/73

ADOPTION OF AGENDA

The agenda of the meeting was adopted after being proposed by Hon. (Dr.) James Kipkosgei Murgor, MP and seconded by Hon. (Dr.) James Nyikal, MP.

AGENDA

1. Prayers
2. Adoption of the Agenda
3. Confirmation of the Minutes
4. Substantive Agenda: Meeting with Cabinet Secretary, Ministry of Health regarding the following Public Petitions
 - i) Public Petition by Ms. Caroline Oreng' on mental health issues and the need for more counsellors in public facilities
 - ii) Public Petition by Hon. David Ole Sankok, MP on hemophilia and other bleeding disorders among patients in Kenya
5. Any Other Business
6. Date of the Next sitting

MIN. NO.NA/DC.H/2019/74

MEETING WITH HON. DAVID OLE SANKOK AND OTHERS ON HEMOPHILIA AND OTHER BLEEDING DISORDERS AMONG PATIENTS IN KENYA

Hon. David Ole Sankok submitted that patients with hemophilia suffered substantially both emotionally and financially. He noted that the conditions' medication was expensive, at about Kshs. 30 per unit, with a patient needing about 3,500 units.

Dr. Kibet said that the patients were at risk now that country was losing donor support progressively. In addition, the international donors providing clotting factor concentrates faced challenges of clearance by customs, who demand Import Declaration Fees (IDF) and Railway Development Levy (RDL).

Mr. James Kago called for availability of all factor concentrates for better management of the disease in the country and that the medical profession and the public should also be informed extensively about the condition.

MIN. NO.NA/DC.H/2019/75:

SUBMISSIONS FROM THE MINISTRY OF
HEALTH REGARDING THE TWO PUBLIC
PETITONS

Public Petition by Ms. Caroline Oreng' on mental health issues and the need for more counsellors in public facilities

Ms. Susan Mochache, Principal Secretary submitted that:

The Ministry of Health was implementing various measures to ensure good mental health of the population and address the diseases associated with mental health conditions. The measures included strengthening of counselling and psychosocial services at all levels of healthcare and the employment of the required human resources for mental health.

The following are some of the strategic actions that would address the issues raised in the petition;

1. The implementation of Kenya Mental Health Policy 2015-2030, which provides a roadmap on strengthening of mental health systems with goal of attaining the highest standards of mental health.
2. The implementation of the Presidential Directive on Mental Health on 1st June, 2019. The Ministry was collaborating with Counties, other Ministries and Stakeholders to implement short and long term multi-sectoral programs which include mental health and psychosocial services in the Workplace, Schools, Colleges and Community settings.
3. The Universal Health Coverage Programme implementation had incorporated mental health services at all levels of care with counselling services within the care pathways and health benefit package. This was aimed at improving the access, equity, quality of services and protection from financial burden.
4. Setting up of a regulatory Board for counsellors and psychologists as stipulated in the Counsellors and Psychologists Act to regulate the training, registration, licensing and service provision.
5. In addition, the Schemes of Service for Counsellors and Psychologists Officer in Health had been developed to guide in recruitment, career progression and the roles and responsibilities.
6. The Kenya Medical Training College had scaled up training programs for mental health professionals across the country to develop more human resources for mental health. KMTC had also started new courses with focus on counselling and psychosocial services such as Higher Diploma on Addiction Counselling and Management at (KMTC-Mathari Campus), and Diploma in Medical Social Work in KMTC – Karuri.
7. Training of Community Health volunteers (CHVs) on counseling skills and low intensity psychosocial interventions such as problem management plus (PM+), Psychological First Aid, Mental Health First Aid, and Interpersonal Therapy (IPT).

8. Integration of counselling services in all healthcare programs; maternal health, surgical, medical, sexual and reproductive health, NCD, rehabilitative and palliative care. The programs have multidisciplinary teams which include psychosocial professionals and all the other health workers are trained in basic counselling skills.
9. The Ministry had trained psychosocial team for emergency and disaster response in collaboration with other agencies.
10. Training of peer to peer counsellors and educators in schools, colleges and communities.

Public Petition by Hon. David Ole Sankok, MP on hemophilia and other bleeding disorders among patients in Kenya

The Principal Secretary submitted that;

1. The clotting factor concentrates are recognized as part of the Ministry of Health Hemophilia treatment guidelines. Hemophilia and other bleeding disorder patients had been receiving care through donated clotting factor concentrates from the World Federation of hemophilia through a memorandum of understanding (MOU signed in November 2016 and ends in 2021) between the Kenyan government and the federation. However, availability of factor concentrates had faced challenges of providing the same in the Health facilities leading to erratic supply.
2. The government through the Ministry of Health, will budget for the factors which are essential and lifesaving before expiration of the MOU. It would also consider patients who require specialized products which are equally expensive.
3. The Ministry is currently receiving factor concentrate donations and distributing through KNH to treating facilities. (total of 3 nationally). It would use the existing purchase and distribution mechanism (KEMSA) to ensure all patients receive products at the nearest health facility.
4. The Ministry through the Pharmacy and Poisons Board will conduct an aggressive market survey on the available advanced pharmaceutical therapies in the market for the management of hemophilia. To enhance smooth availability of drugs for this condition the Board will provide support to manufacturers during registration of their products.
5. The Ministry had also been collaborating with the County governments and other stakeholders (Kenya Hemophilia Association) in establishing treatment centers in “hot spots” while developing KNH and MTRH as hemophilia comprehensive care clinics (HCCC). More centers would be established once products are made readily available.
6. The Ministry had developed adequate capacity for diagnosis and monitoring of patients at KNH and MTRH, this was being extended at Coast PGH, Muranga and Kisii County Referral Hospitals. These counties and others that would be included in the treatment portfolio will be capacitated to provide diagnostic tests. The sustainability of the reagents for testing will be a function of the county

governments as UHC is being rolled out. Ministry of Health will continue to provide policy direction on testing.

7. Health care professionals are being trained on care of various types of diseases including hemophilia and other bleeding disorders. The Ministry is also developing the disability guidelines which would include all the genetically inherited disease conditions like hemophilia.
8. Hemophilia was currently managed through the existing NHIF scheme done through integrated disease management approach. The patients with hemophilia would greatly benefit with full operationalization of UHC.

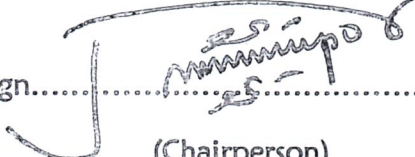
Committee Resolution

The Committee resolved to engage with the Ministry of National Treasury and Kenya Revenue Authority in order to address the issues raised regarding imposition of Import Declaration Fees (IDF) and Railway Development Levy (RDL) on donors drugs meant for hemophilia and other life threatening conditions.

MIN. NO.NA/DC.H/2019/76

ADJOURNMENT

There being no other business, the meeting adjourned at 12.48 pm. Next Sitting would be on Thursday, 19th September, 2019.

Sign.....
(Chairperson)

Date.....19/09/2019

MINUTES OF THE THIRTY FIFTH (35TH) SITTING OF THE DEPARTMENTAL COMMITTEE ON HEALTH HELD IN THE SMALL BOARDROOM, 9TH FLOOR, HARAMBEE SACCO PLAZA, PARLIAMENT BUILDINGS ON THURSDAY 1ST AUGUST 2019 AT 10.00 A.M.

PRESENT

1. Hon. (Dr.) Swarup Ranjan Mishra, MP – Vice Chairperson
2. Hon. Martin Peters Owino, MP
3. Hon. (Dr.) Eseli Simiyu, MP
4. Hon. (Dr.) James Kipkosgei Murgor, MP
5. Hon. (Dr.) Mohamed Dahir Duale, MP
6. Hon. Patrick Munene Ntwiga, MP
7. Hon. Zachary Kwenya Thuku, MP

ABSENT WITH APOLOGY

1. Hon. Sabina Chege, MP - Chairperson
2. Hon. (Dr.) James Nyikal, MP
3. Hon. Kipsengeret Koros, MP
4. Hon. David Ochieng' MP
5. Hon. Stephen Mule, MP
6. Hon. Tongoyo Gabriel Koshal, MP
7. Hon. Mercy Wanjiku Gakuya, MP
8. Hon. Esther M. Passaris, MP

ABSENT

1. Hon. Gladwell Jesire Cheruiyot, MP
2. Hon. Alfred Agoi Masadia, MP
3. Hon. Muriuki Njagagua, MP
4. Hon. Prof. Mohamud Sheikh Mohamed, MP

IN ATTENDANCE

NATIONAL ASSEMBLY SECRETARIAT

1. Mr. Victor Weke - Clerk Assistant I
2. Mr. Hassan Othowa - Principal Research Officer II

PETITIONERS

1. Ms. Carol Ajwang' Orenge' - Petition on mental health issues and the need for more counsellors in public facilities
2. Hon. David Ole Sankok, MP- Petition on management of hemophilia
3. Dr. Kibet Shikuku
4. Mr. Carlos Maube Odera
5. Mr. James Kago

MINISTRY OF HEALTH

1. Dr. Peter Hayombe - Health Summit Consultant
2. Ms. Mary Achieng' - Health Summit Consultant

MIN. NO. NA/C.H/2019/136:

PRELIMINARIES

The Vice-chairperson called the meeting to order at 10.12 am and said a prayer, followed by a round of introductions.

MIN. NO. NA/DC.H/2019/137:

ADOPTION OF AGENDA

The agenda of the meeting was adopted as hereunder after being proposed by Hon. Martin Peters Owino, MP and seconded by Hon. Patrick Munene, MP.

AGENDA

1. Prayers
2. Adoption of the Agenda
3. **Confirmation of the Minutes**
4. Substantive Agenda:
 - i) Meeting with Ms. Caroline Orenge' regarding petition on mental health issues and the need for more counsellors in public facilities
 - ii) Meeting with Hon. David Ole Sankok, MP regarding petition on hemophilia and other bleeding disorders among patients in Kenya
 - iii) Meeting with consultants from the Ministry of Health on the upcoming Health Summit
5. Any Other Business
6. Date of the Next sitting

MIN. NO. NA/DC.H/2019/138:

CONFIRMATION OF MINUTES OF PREVIOUS SITTING

Minutes of the 34th sitting held on 30th July, 2019 were confirmed as a true record of the proceedings after being proposed by Hon. (Dr.) James Murgor, MP and seconded by Hon. (Dr.) Eseli Simiyu, MP.

There were no matters arising.

MIN. NO. NA/DC.H/2019/139:

MEETING WITH MS. CAROLINE ORENGE' ON PETITION ON MENTAL HEALTH ISSUES AND THE NEED FOR MORE COUNSELLORS IN PUBLIC FACILITIES

Ms. Caroline Orenge' submitted that her petition was driven by the fact that the country had of late witnessed an increase in murders and challenges attributable to mental health issues. As a practicing counselling psychologist, she had seen various patients admitted to hospital, but whose ailments were a direct consequence of mental health issues.

Her petition had the following prayers;

- i) There be a sensitization of the community of signs and symptoms of mental health to help the society aware when to take action to avoid misfortunes. Just the way it was done in HIV/AIDS, maternal health, polio, etc.;
- ii) Grading of counsellors and give them job groups so that they can be employed in government facilities and help those who can't afford private institutions;

- iii) Detachment of counseling from guidance and counselor teachers and make it a department of its own so that the teachers can concentrate in academics and counselors to concentrate on the child's mental health fully;
- iv) Have counselors attached to psychiatrics so that as a patient is taking medication, a counselor is carrying out therapies to minimize relapse and reduce pill taking;
- v) Involve community psychology programs of child guidance; halfway houses; programs for the rehabilitation of alcoholics and drug addicts, help youth adjust with concerns of planning career and young adulthood, help adjustment in middle age crisis and old age crisis;
- vi) Make sure that all work places have a psychologist on the ground to help staff cope with workload, office politics, help approach problems with active attitude so that they can channel anxiety into useful effort instead of carrying it home and pouring out on their spouses and children;
- vii) Guidance in children's court to include pro-bono services from lawyers and psychologists in order to help rehabilitate child offenders without necessarily subjecting them to a jail term.

MIN. NO.NA/DC.H/2019/140:

MEETING WITH HON. DAVID OLE
SANKOK AND OTHERS ON
HEMOPHILIA AND OTHER BLEEDING
DISORDERS AMONG PATIENTS IN
KENYA

Hon. David Ole Sankok led his other petitioners in making a case for their petition. He submitted that patients with hemophilia suffered substantially reduced quality of life on account of frequent bleeding episodes and disorders most of which are life threatening.

Dr. Kibet submitted that hemophilia was congenital but could also be acquired. Patients lacked some protein, X-chromosome, which affected clotting of blood, leaving patients with the risk of bleeding to death. The disease mainly affected men.

Prevalence stood at 1 out of 10,000 individuals, with approximately 5,000 affected. The Association of Hemophilia patients in Kenya had managed to reach 700 of them.

Necessary drugs had not been classified by the Ministry in its essential drugs list and was thus not procured by KEMSA. The medication was expensive, at about Kshs. 30 per unit, with a patient needing about 3,500 units. Local patients therefore depended majorly on donations from an international donor. The donor however faced challenges of clearance of these donations by customs, who demanded taxes.

The petitioners prayed that the Committee;

- i) Recommends the recognition of clotting factor concentrates as part of hemophilia's treatment and facilitates their availability in the Kenyan market;
- ii) Recommends to the Ministry of Health the establishment of more treatment centres, the improvement of diagnostic capacity, the facilitation of training of health care workers, the review of medical-training curriculum to include hemophilia and other bleeding disorders management and care in all medical training institutions, and funding support to aid in creation and facilitation to hemophilia disease awareness;
- iii) Recommends the recognition of hemophilia as a disabling condition to enable the recognition of hemophilia patients with the National Council of Persons with Disability and support the coverage of the condition by the NHIF.

The Committee resolved to engage with the Ministry of Health on the various issues raised in the two petitions before making its recommendations.

MIN. NO.NA/DC.H/2019/141:

MEETING WITH CONSULTANTS ON
THE HEALTH SUMMIT

The secretariat briefed the Committee of progress so far made by the technical committee hosted at Afya House in preparation for the summit. The summit would be preceded by a pre-summit on Wednesday 7th August, 2019, before the summit scheduled for 14th & 15th August, 2019, at the Safari Park Hotel.

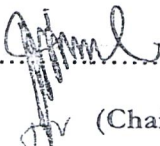
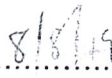
Dr. Hayombe informed the Committee that his brief was to meet with various stakeholders to understand their views on the various issues at hand, before the summit.

The Committee provided the background to the summit, especially the fact that it is they who called for the summit to sort out various issues threatening provision of health services in the country, including devolution, a failed referral system, human resources, health financing, leadership and governance. The Committee would meet on Tuesday 6th August, 2019 to adopt its position paper for presentation before the pre-summit.

MIN. NO.NA/DC.H/2019/142:

ADJOURNMENT

There being no other business, the meeting adjourned at 12.35 pm. Next Sitting would be on Tuesday, 6th August, 2019 at 9.30 am.

Sign.......... Date..........
(Chairperson)

REPUBLIC OF KENYA



Approved.

RA
SNA
26/6/19

TWELFTH PARLIAMENT (THIRD SESSION)

THE NATIONAL ASSEMBLY

(No. 60 of 2019)

PUBLIC PETITION

REGARDING MANAGEMENT OF HEMOPHILIA AND OTHER BLEEDING
DISORDERS AMONG PATIENTS IN KENYA

I, the **UNDERSIGNED**, on behalf of Hemophilia Patients of Kenya,

DRAW the attention of the House to the following:-

1. **THAT**, the right to health is a fundamental human right guaranteed in the Constitution of Kenya, with Article 43(1)(a) stipulating that every person has the right to the highest attainable standard of health including the right to health care services;
2. **THAT**, patients with Hemophilia suffer substantially reduced quality of life on account of frequent bleeding episodes and disorders most of which are life threatening or lead to disabling joint disease (arthropathy) and shortened life expectancy;
3. **THAT**, methods of treatment and management of hemophilia are costly and typically time-consuming, and thus end up placing a considerable burden on patients' physical, financial and psychological well-being;
4. **THAT**, currently the only treatment product recognized by the Ministry of Health in its Essential Drugs List is blood components, which means that the Kenya Medical Services Authority (KEMSA) cannot purchase the appropriate drugs to be used locally and even pharmaceuticals dealing in clotting factor concentrates cannot conveniently import the medicine into the country;
5. **THAT**, the prevalence of Hemophilia is 1 in every 10,000 individuals, and out of the approximately 4,500 hemophilia patients in Kenya, only 740 patients (or 16% of the total) have been identified, hence the need for sustained awareness of the condition;

PUBLIC PETITION REGARDING MANAGEMENT OF HEMOPHILIA AND OTHER

BLEEDING DISORDERS AMONG PATIENTS IN KENYA

6. **THAT**, the clotting factor concentrate donations received at present are insufficient and inconsistent, giving 30% factor level for the 740 (16%) patients that have so far been identified and diagnosed, and thus at times forcing patients to revert to blood related products that require hospital admissions for transfusion;
7. **THAT**, the current donation program that purchases clotting factor concentrates for the patients has a factor concentrates deficiency of 70% that needs to be covered through purchase, and the same ends in the next two years;
8. **THAT**, there are currently only three fully operational Hemophilia treatment centers in the country in the face of the need to make treatment and care available in all referral hospitals and facilities which should have testing and diagnosis machines that can undertake basic coagulation tests besides supportive treatment including physiotherapy;
9. **THAT**, there is limited knowledge about the condition amongst clinicians hence complicating their ability to identify, diagnose and appropriately refer patients to established facilities;
10. **THAT**, efforts to sufficiently address the plight of hemophilia patients have not borne much fruit; and
11. **THAT**, the issues in respect of which this Petition is made are not pending before any Court of Law, or any Constitutional or Statutory body.

THEREFORE, your humble **PETITIONERS** pray that the National Assembly, through the Departmental Committee on Health;

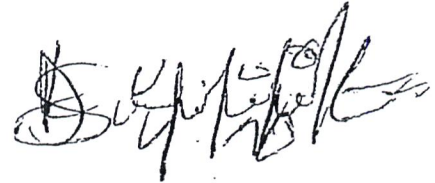
- i. Recommends the recognition of Clotting Factor Concentrates as part of Hemophilia's treatment and facilitates their availability in the Kenyan market;
- ii. Recommends to the Ministry of Health the establishment of more treatment centers, the improvement of diagnostic capacity, the facilitation of training of health care workers, the review of medical-training curriculum to include Hemophilia and other bleeding disorders' management and care in all Medical Training Institutions, and funding support to aid in creation and facilitation of hemophilia disease awareness;

PUBLIC PETITION REGARDING MANAGEMENT OF HEMOPHILIA AND OTHER
BLEEDING DISORDERS AMONG PATIENTS IN KENYA

- iii. Recommends the recognition of Hemophilia as a disabling condition to enable the registration of Hemophilia patients with the National Council of ~~Persons with Disability and support the coverage of the condition by the~~ National Hospital Insurance Fund (NHIF); and
- iv. Makes any other recommendations that it deems fit in the circumstances of this matter.

And your **PETITIONERS** will ever pray.

PRESENTED BY: -



HON. DAVID OLE SANKOK, MP
NOMINATED MEMBER

Date:.....

20/6/19.