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REPUBLIC OF KENYA



PAPERS LAID	
DATE	16 <sup>th</sup> JUNE, 2022
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COMMITTEE	HEALTH
CLERK AT THE TABLE	S. C. MA

PARLIAMENT OF KENYA

THE SENATE

TWELFTH PARLIAMENT

SIXTH SESSION

THE STANDING COMMITTEE ON HEALTH

REPORT ON THE PETITION BY MS. MARIO JUMA AND OTHERS ON THE CHALLENGES FACED BY PATIENTS SUFFERING FROM MULTIPLE SCLEROSIS AND NEUROMYELITIS OPTICA

Clerk's Chambers,  
First Floor,  
Parliament Buildings,  
NAIROBI.

③ Hon. Speaker  
You may approve for  
tabling. *[Signature]*  
15/6/22

JUNE, 2022

*DC-E.G.*  
Recommended & Forwarded for processing.  
Forwarded for your approval  
15/6/2022

Approved  
*[Signature]*  
16/06/2022

## PREFACE

**Mr. Speaker Sir,**

The Senate Standing Committee on Health is established under standing order 218(3) of the Senate Standing Orders and is mandated to, “*consider all matters relating to medical services, public health and sanitation.*”

### **Committee Membership**

The Membership of the Committee is composed of the following:

1. Sen. (Dr.) Michael Mbiti, MP. - Chairperson
2. Sen. Mary Seneta, MP. - Vice-Chairperson
3. Sen. Beth Mugo, EGH, MP.
4. Sen. Beatrice Kwamboka, MP.
5. Sen. (Prof.) Samson Ongeru, EGH, MP.
6. Sen. (Dr.) Abdullahi Ali Ibrahim, MP.
7. Sen. Fred Outa, MP.
8. Sen. Millicent Omanga, MP.
9. Sen. Ledama Olekina, MP.

**Mr. Speaker,**

On 11<sup>th</sup> November, 2020, a petition by Ms. Marion Juma and three others concerning the challenges faced by patients suffering from Multiple Sclerosis (MS) and Neuromyelitis Optica (NMO) was tabled before the Senate and committed to the Standing Committee on Health pursuant to Standing Order No. 226(1) of the Senate Standing Orders.

**Mr. Speaker Sir,**

The petition sought to move the Senate to: initiate the subsidization of drugs for the management of MS and NMO; intervene to ensure access to qualified Specialists by patients suffering from MS and NMO; initiate the recognition of MS and NMO patients

as persons with disabilities (PWDs) who are therefore exempt from tax; initiate free counseling and therapy services; initiate the process of allocating funds for the creation of public awareness on the conditions; and, intervene to ensure that patients with MS and NMP are covered by NHIF as in the case of cancer patients who get free drugs and chemotherapy.

**Mr. Speaker,**


In conducting its investigations, the Committee met with key parties in relation to the petition, chiefly: the Petitioners, the Ministry of Health and the National Health Insurance Fund. The Committee findings and determinations arising from this process are contained in this report.

**Mr. Speaker Sir,**

The Standing Committee on Health wishes to thank the Offices of the Speaker and Clerk of the Senate for their support during the process of considering this petition.

**Mr. Speaker Sir,**

It is now my pleasant duty and privilege to present this report of the Standing Committee on Health, for consideration and approval by the House pursuant to Standing Order No. 226(2) of the Senate Standing Orders.

Signed.....  ..... Date.....15/6/2022.....

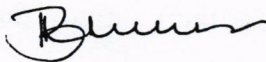
**SEN. MBITO MICHAEL MALING'A, MP**

**CHAIRPERSON, STANDING COMMITTEE ON HEALTH**

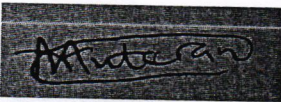
**ADOPTION OF THE REPORT OF THE STANDING COMMITTEE ON HEALTH OF THE SENATE**

**We, the undersigned Members of the Standing Committee on Health of the Senate, do hereby append our signatures to adopt the Report-**

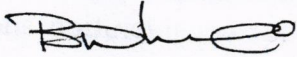
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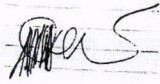
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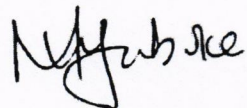
6. Sen. (Dr) Abdullahi Ali Ibrahim, MP

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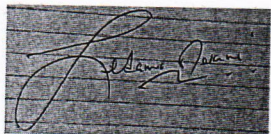
7. Sen. Fred Outa, MP

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8. Sen. Millicent Omanga, MP

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9. Sen. Ledama Olekina, MP

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**ABBREVIATIONS**

MOH	-	Ministry of Health
MS	-	Multiple Sclerosis
NHIF	-	National Health Insurance Fund
NMO	-	Neuromyelitis Optica

## EXECUTIVE SUMMARY

On 11<sup>th</sup> November, 2020, a petition by Ms. Marion Juma and three others concerning the challenges faced by patients suffering from Multiple Sclerosis (MS) and Neuromyelitis Optica (NMO) was tabled before the Senate and committed to the Standing Committee on Health pursuant to Standing Order No. 226(1) of the Senate Standing Orders.

The petition was broadly in relation to the challenges faced by patients with MS and NMO in accessing timely, quality healthcare, and avoiding catastrophic health expenditures. To this effect, the petitioners averred that:-

- (a) Multiple Sclerosis (MS) is a rare autoimmune disease that causes the body's own defenses to destroy neurons in the brain and spinal cord;
- (b) Neuromyelitis Optica Spectrum Disorder (NMOSD/NMO), also known as Devic Disease, is a chronic disorder of the brain and spinal cord that is dominated by inflammation of the optic nerve (optic neuritis) and inflammation of the spinal cord (myelitis);
- (c) Both MS and NMO are debilitating diseases that affect the nerves. In patients with MS or NMO, the body destroy myelin, the fatty insulating material that covers the nerve fibers that form part of the nervous system, which controls all bodily functions;
- (d) Demyelinated nerves cannot transmit impulses to the brain or spinal cord and from the muscles in the body, Consequently, MS/NMO patients sometimes have difficulties with such simple tasks like swallowing food, blinking, vague vision, controlling their bladder or limbs, or focusing their eyes on an object;
- (e) Symptoms of MS depend on which part of the nervous system has been targeted by the disease, and that common problems include fatigue, continence problems, sexual problems, constipation, pain, cognitive changes, altered sensation and muscular and visual changes;
- (f) A person with MS or NMO may struggle to come to terms with their disease. They might fear for their future or suffer from low self esteem because of the physical changes they are experiencing;

- (g) MS can target virtually any part of the nervous system. It can also affect the nerves of the reproductive organs, which leads to changes in sexual function including slow arousal time, reduced libido or desire and altered orgasmic responses;
- (h) The growing burden of MS and NMO has been raised as one of the most significant barriers to the attainment of Universal Healthcare (UHC);
- (i) NHIF does not cover MS and thus most patients end up as PWDs;
- (j) Best efforts had been made to have these issues addressed by the relevant authorities, all of which had failed to give a satisfactory response; and
- (k) None of the issues raised in the Petition was pending in any court of the law, or Constitutional or legal body.

In their prayers, the petitioners requested that the Senate :

- a) Initiates the subsidy of the price of medicine to a more affordable price. A DMD (disease-modifying drug) or weekly injection can go as high as KShs. 100,000;
- b) Intervenes in the matter with a view to ensuring that there are more qualified specialists in all hospitals, especially district hospitals. MS and NMO resemble several other autoimmune diseases. A pinpoint diagnosis would help with the management of the disease before one gets to the progressive stage of the disease which is rarely manageable;
- c) Initiates the recognition of this group as Persons with Disabilities (PWDs) and, therefore, be exempted from taxation;
- d) Initiates free counseling and therapy services;
- e) Initiates the process for allocation of funds to carry out awareness campaigns that will involve the Government and private sector to understand the different conditions of the diseases and management of the patients; and

- f) Intervenes for the undersigned group to obtain a proper cover under the National Hospital Insurance Fund (NHIF) like the case of cancer patients who get free drugs and chemotherapy.

In respect of the prayers made in the petition, the Committee made the following determinations:

1. *Prayer One: Initiates the subsidy of the price of medicine to a more affordable price;*

**Committee Response:** The Committee in respect of this prayer noted that the MoH had put in place interventions aimed at increasing access to, and affordability of care for patients with MS/NMO. Specifically, the MoH had included Disease-Modifying Drugs (DMDs) necessary for the management of MS/NMO in the Kenya Essential Drugs List (KEDL). These include but are not limited to Etanercept, Abatacept, Golimumab, Infliximab, Ritximab and Tocilisumab amongst others.

However, whereas the Committee acknowledged the government's efforts in providing for the inclusion of DMDs in the KEDL; and whereas the Committee acknowledged that it represents an important step in providing for subsidized care and management for patients with MS/NMO; the Committee nevertheless noted that there is a need for the MoH, the Council of Governors (COG) and County Governments to put mechanisms in place to ensure that DMDs for the treatment and management of MS/NMO are prioritized for procurement, and are availed at all public health facilities through Kenya Medical Supplies Authority (KEMSA).

2. *Prayer Two: Intervenes in the matter with a view to ensuring that there are more qualified specialists in all hospitals, especially district hospitals. MS and NMO resemble several other autoimmune diseases. A pinpoint diagnosis would help with the management of the disease before one gets to the progressive stage of the disease which is rarely manageable;*

**Committee Response:** In respect of this prayer, the Committee observed that whereas the MoH had put in place various interventions aimed at addressing the shortage of Specialists needed for the management and care of patients with MS/NMO, including, but not limited to: the recruitment of three neurologists and

three ophthalmologists through the Kenyan Cuban Project; and the provision of scholarships for five (5) Neurologists, thirteen (13) Ophthalmologists and ten (10) Psychiatrists, there was still a need for the MoH to explore further avenues for increasing the number of specialists and subspecialists in the country.

These include, but are not limited to: the introduction of collegiate and on-site training programs to fast-track and expand training opportunities; transfer of post-graduate training for Specialist Doctors from County Governments to the National Government; deployment of specialists-in-training from post-graduate training institutions to satellite health facilities in the field; promotion of e-Health and telemedicine services; and, forging of partnerships and collaboration with medical professional associations such as ArthRheuma to develop guidelines and curriculae for training medical officers, clinical officers, nurses and patients.

**3. *Prayer Three: Initiates the recognition of this group as Persons with Disabilities (PWDs) and, therefore, get tax exemption;***

**Committee Response:** The Committee in respect of this prayer acknowledged that patients with MS/NMO can develop functional limitations that progressively worsen over time and result in actual disability.

The Committee further observed that as per submissions made by the MoH, the function of categorizing and assessing PWDs had been devolved to the level of County Directors of Health.

Further, that upon establishing and categorizing PWDs at county level, mechanisms had been put in place for the transmission of such information to the National Council of Persons with Disabilities (NCPD) for purposes of facilitating registration.

Nevertheless, the Committee observed that patients with MS/NMO are inherently, and disproportionately at risk of developing severe disability. As such, the MoH and the NCPD need to go a step further and put mechanisms in place to provide for the early detection of MS/NMO with a view towards recognising, mitigating, and providing socio-economic relief from the more debilitating effects of the disease(s) before they progress to actual disability.

**4. *Prayer Four: Initiate Free Counseling and Therapy***

The Committee in respect of this prayer noted that according to submissions made by the MoH, professional counseling services are now available at Level 4, 5 and 6 hospitals to all patients who need them including patients suffering from MS/NMO.

Further, the Committee observed that under the UHC program, NHIF has provided counseling and mental health packages which are available for use by MS/NMO patients.

5. *Prayer Five: Initiates the process for allocation of funds to carry out awareness campaigns that will involve the Government and private sector to understand the different conditions of the diseases and management of the patient.*

**Committee Response:** In respect of this prayer, the Committee noted that under the UHC Program, the MoH in collaboration with County Governments need to develop a communication strategy to educate, raise awareness and promote awareness of autoimmune diseases amongst Kenyans.

Further, the Committee observed that the MoH, relevant health regulatory bodies and health worker associations should act to scale-up continuous medical education on autoimmune diseases like MS and NMO.

6. *Prayer Six: Intervenes for the undersigned group to obtain a proper cover under the National Hospital Insurance Fund (NHIF) like the case of cancer patients who get free drugs and chemotherapy; and*

**Committee Response:** In respect of this prayer, the Committee noted that NHIF only covers MS and NMO diseases in the benefits packages that it offers under its managed schemes e.g. Civil Servant Cover.

However, for patients on ordinary NHIF cover, the benefit package is limited to dialysis, or procedures currently covered under the national scheme. This has left patients with MS and NMO unable to access needed treatment, and exposed them to catastrophic health expenditure.

The Committee further noted that unlike cancer patients who had been granted access to drugs and chemotherapy under NHIF, no special provision had been made for patients with MS/NMO. This was in itself discriminatory. To address

this, the Committee observed that NHIF should develop a special cover for patients with MS/NMO aimed at ensuring that they receive the highest attainable standards of care in line with Article 43 of the Constitution, without incurring catastrophic health expenditure.

In light of the above, the Committee resolved that:

1. This report be dispatched to the Ministry of Health for purposes of reporting back to the Senate on the progress it has made in respect of: ensuring the prioritization and procurement of DMDs for the management and care of patients with MS/NMO at all public health facilities through KEMSA; scaling-up the availability of Specialist care; facilitating assessment processes for patients with MS/NMO for purposes of the providing for the early detection, recognition, mitigation and socio-economic relief of patients suffering from the debilitating effects of MS/NMO before they progress to actual disability; and, scaling up public awareness and continuous medical education on autoimmune diseases like MS/NMO within **six months** receipt of this report.
2. This report be dispatched to the National Health Insurance Fund (NHIF) for purposes of developing and rolling out a special cover for patients with MS/NMO within a period of **six months**. This cover should be aimed at ensuring that patients with MS/NMO receive the highest attainable standards of care in line with Article 43 of the Constitution, without incurring catastrophic health expenditure.
3. This report be dispatched to the National Council for Persons with Disabilities for purposes of proposing mechanisms for the development, and rolling-out of interventions for the early detection, mitigation, and socio-economic relief of patients suffering from the debilitating effects of MS/NMO before they progress to actual disability within a period of **six months**.

## **CHAPTER ONE**

### **INTRODUCTION**

#### **1. Background**

On 11<sup>th</sup> November, 2020, a petition by Ms. Marion Juma and three others concerning the challenges faced by patients suffering from Multiple Sclerosis (MS) and Neuromyelitis Optica (NMO) was tabled before the Senate and committed to the Standing Committee on Health pursuant to Standing Order No. 226(1) of the Senate Standing Orders.

The petition was broadly in relation to the challenges faced by patients with MS and NMO in accessing timely, quality healthcare, and avoiding catastrophic health expenditures.

#### **2. Summary of Allegations Raised in the Petition**

A summary of the challenges faced by patients with MS/NMO as contained in the petition are outlined below: -

- (a) Multiple Sclerosis (MS) is a rare autoimmune disease that causes the body's own defenses to destroy neurons in the brain and spinal cord;
- (b) Neuromyelitis Optica Spectrum Disorder (NMOSD/NMO), also known as Devic Disease, is a chronic disorder of the brain and spinal cord that is dominated by inflammation of the optic nerve (optic neuritis) and inflammation of the spinal cord (myelitis);
- (c) Both MS and NMO are debilitating diseases that affect the nerves. In patients with MS or NMO, the body destroys myelin, the fatty insulating material that covers the nerve fibers that form part of the nervous system, which controls all bodily functions;
- (d) Demyelinated nerves cannot transmit impulses to the brain or spinal cord and from the muscles in the body. Consequently, MS/NMO patients sometimes have difficulties with such simple tasks like swallowing food,

blinking, vague vision, controlling their bladder or limbs, or focusing their eyes on an object;

- (e) Symptoms of MS depend on which part of the nervous system has been targeted by the disease, and that common problems include fatigue, continence problems, sexual problems, constipation, pain, cognitive changes, altered sensation and muscular and visual changes;
- (f) A person with MS or NMO may struggle to come to terms with their disease. They might fear for their future or suffer from low self esteem because of the physical changes they are experiencing;
- (g) MS can target virtually any part of the nervous system. It can also affect the nerves of the reproductive organs, which leads to changes in sexual function including slow arousal time, reduced libido or desire and altered orgasmis responses;
- (h) The growing burden of MS and NMO has been raised as one of the most significant barriers to the attainment of Universal Healthcare (UHC);
- (i) NHIF does not cover MS and thus most patients end up as PWDs;
- (j) Best efforts had been made to have these issues addressed by the relevant authorities, all of which had failed to give a satisfactory response; and
- (k) None of the issues raised in the Petition was pending in any court of the law, or Constitutional or legal body.

### **3. Prayers to the Senate**

The petitioners therefore prayed that the Senate -

- a) Initiates the subsidy of the price of medicine to a more affordable price. A DMD (disease-modifying drug) or weekly injection can go as high as KShs. 100,000;
- b) Intervenes in the matter with a view to ensuring that there are more qualified specialists in all hospitals, especially district hospitals. MS and NMO resemble several other autoimmune diseases. A pinpoint diagnosis would help with the

management of the disease before one gets to the progressive stage of the disease which is rarely manageable;

- c) Initiates the recognition of this group as Persons with Disabilities (PWDs) and, therefore, be exempted from taxation;
- d) Initiates free counseling and therapy services;
- e) Initiates the process for allocation of funds to carry out awareness campaigns that will involve the Government and private sector to understand the different conditions of the diseases and management of the patients
- f) Intervenes for the undersigned group to obtain a proper cover under the National Hospital Insurance Fund (NHIF) like the case of cancer patients who get free drugs and chemotherapy;

## CHAPTER TWO

### LEGAL AND POLICY PROVISIONS RELATING TO THE PETITION

#### 1. Role and Mandate of Parliament

Articles 94 as read together with Article 96 of the Constitution provides for the role of Parliament in general, and the Senate in particular. 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.

#### 2. Right to Petition Parliament

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.”*

Further, Standing Order 226 the Senate Standing Order outlines the procedure for the committal of a petition to a Committee and transmission of its decision to the Petitioner. The Standing Committee on Health is mandated to consider all matters related to medical services, public health and sanitation. Further, the Petition to Parliament (Procedure) Act, 2012 and the Standing Orders of the Senate provide for the procedure to be followed in the submission, processing and consideration of a Petition.

#### 3. Right to the Highest Attainable Standard of Health

Article 43 (1)(a) of the Constitution guarantees every person the right to ‘*the highest attainable standard of health, which includes the right to health care services, including reproductive health care*’.

#### 4. Analysis of the Law in regard to the Prayers

##### i) Subsidization of Medicines

- a. Fourth Schedule of the Constitution provides that the National Government shall develop *health policy*.
- b. Section 24 (f) of the Health Act provides that the National Government shall manage and be responsible for *any health care function or service* that is not otherwise assigned to the county government.
- c. Section 19 of the Health Act provides that county governments shall procure and manage *health supplies*. Section 67 (1) of the Health Act further provides that *the procurement for the public health services of health products and technologies shall be undertaken in line with the Public Procurement and Disposal Act as well as the intergovernmental arrangements for medicine and medical products agreed upon*.

ii) **Employment of Specialist Doctors**

- a. Article 235 of the Constitution states that *a county government is responsible, within a framework of uniform norms and standards prescribed by an Act of Parliament, for—*
  - (a) *establishing and abolishing offices in its public service;*
  - (b) *appointing persons to hold or act in those offices, and confirming appointments; and*
  - (c) *exercising disciplinary control over and removing persons holding or acting in those offices.*
- b. The Fourth schedule to the Constitution provides that the *National government is responsible for capacity building and technical assistance to the counties*.
- c. Section 30 of the Health Act provides that the Kenya Health Human Resource Advisory Council shall review policy and establish uniform norms and standards for *management and rotation of specialists*.
- d. Section 107 of the Health Act provides that *the Cabinet Secretary shall issue administrative guidelines and regulations on professional post basic training of all health workers for implementation in line with the national training policy for health professionals*. It further provides that *all specialists shall be treated*

*as a national asset in order to sustain internship training and specialist services to ensure standards and equity.*

**iii) Tax Exemption**

- a. *Section 2 of the Persons' with Disabilities Act defines "disability" to mean a physical, sensory, mental or other impairment, including any visual, hearing, learning or physical incapability, which impacts adversely on social, economic or environmental participation;*
- b. *Section 12 (3) of the Act further provides that an employee with a disability shall be entitled to exemption from tax on all income accruing from his employment; and*
- c. *Section 35 (1) of the Act further provides that all persons with disabilities who are in receipt of an income may apply to the Minister responsible for finance for exemption from income tax and any other levies on such income.*

**iv) Medical Cover under the National Hospital Insurance Fund**

*Section 22 of the National Hospital Insurance Fund Act provides in subsection (3) the benefits payable from the Fund shall be limited to expenses incurred in respect of drugs, laboratory tests and diagnostic services, surgical, dental or medical procedures or equipment; physiotherapy care and doctors' fees, food and boarding costs, subject to such limits, regulations and conditions as the Board may, in consultation with the Minister, prescribe.*

**v) Allocation of funds to carry out awareness campaigns on the disease and management of patients**

*Article 186 (3) of the Constitution provides that a function or power not assigned by this Constitution or national legislation to a county is a function or power of the national government.*

## CHAPTER THREE

### COMMITTEE PROCEEDINGS

In conducting its investigations, on diverse dates, the Committee met with key parties in relation to the petition including:

1. The Petitioners
2. The Ministry of Health
3. The National Health Insurance Fund (NHIF)

The minutes of the above meetings have been attached to this report as *Annex 3*.

Further to the above, written memoranda as submitted to the Committee by the Ministry of Health and NHIF have been annexed to this report for reference purposes.

## CHAPTER FOUR

### COMMITTEE DETERMINATIONS

Following its proceedings, in respect of the prayers made in the petition, the Committee made the following determinations:

7. *Prayer One: Initiates the subsidy of the price of medicine to a more affordable price;*

**Committee Response:** The Committee in respect of this prayer noted that the MoH had put in place interventions aimed at increasing access to, and affordability of care for patients with MS/NMO. Specifically, the MoH had included Disease-Modifying Drugs (DMDs) necessary for the management of MS/NMO in the Kenya Essential Drugs List (KEDL). These include but are not limited to Etanercept, Abatacept, Golimumab, Infliximab, Ritximab and Tocilisumab amongst others.

However, whereas the Committee acknowledged the government's efforts in providing for the inclusion of DMDs in the KEDL; and whereas the Committee acknowledged that it represents an important step in providing for subsidized care and management for patients with MS/NMO; the Committee nevertheless noted that there is a need for the MoH, the Council of Governors (COG) and County Governments to put mechanisms in place to ensure that DMDs for the treatment and management of MS/NMO are prioritized for procurement, and are availed at all public health facilities through Kenya Medical Supplies Authority (KEMSA).

8. *Prayer Two: Intervenes in the matter with a view to ensuring that there are more qualified specialists in all hospitals, especially district hospitals. MS and NMO resemble several other autoimmune diseases. A pinpoint diagnosis would help with the management of the disease before one gets to the progressive stage of the disease which is rarely manageable;*

**Committee Response:** In respect of this prayer, the Committee observed that whereas the MoH had put in place various interventions aimed at addressing the shortage of Specialists needed for the management and care of patients with MS/NMO, including, but not limited to: the recruitment of three neurologists and three ophthalmologists through the Kenyan Cuban Project; and the provision of scholarships for five (5) Neurologists, thirteen (13) Ophthalmologists and ten (10) Psychiatrists, there was still a need for the MoH to explore further avenues for increasing the number of specialists and subspecialists in the country.

These include, but are not limited to: the introduction of collegiate and on-site training programs to fast-track and expand training opportunities; transfer of post-graduate training for Specialist Doctors from County Governments to the National Government; deployment of specialists-in-training from post-graduate training institutions to satellite health facilities in the field; promotion of e-Health and telemedicine services; and, forging of partnerships and collaboration with medical professional associations such as ArthRheuma to develop guidelines and curriculae for training medical officers, clinical officers, nurses and patients.

9. *Prayer Three: Initiates the recognition of this group as Persons with Disabilities (PWDs) and, therefore, get tax exemption;*

**Committee Response:** The Committee in respect of this prayer acknowledged that patients with MS/NMO can develop functional limitations that progressively worsen over time and result in actual disability.

The Committee further observed that as per submissions made by the MoH, the function of categorizing and assessing PWDs had been devolved to the level of County Directors of Health.

Further, that upon establishing and categorizing PWDs at county level, mechanisms had been put in place for the transmission of such information to the National Council of Persons with Disabilities (NCPD) for purposes of facilitating registration.

Nevertheless, the Committee observed that patients with MS/NMO are inherently, and disproportionately at risk of developing severe disability. As such, the MoH and the NCPD need to go a step further and put mechanisms in place to provide for the early detection of MS/NMO with a view towards recognising, mitigating, and providing socio-economic relief from the more debilitating effects of the disease(s) before they progress to actual disability.

**10. *Prayer Four: Initiate Free Counseling and Therapy***

The Committee in respect of this prayer noted that according to submissions made by the MoH, professional counseling services are now available at Level 4, 5 and 6 hospitals to all patients who need them including patients suffering from MS/NMO.

Further, the Committee observed that under the UHC program, NHIF has provided counseling and mental health packages which are available for use by MS/NMO patients.

**11. *Prayer Five: Initiates the process for allocation of funds to carry out awareness campaigns that will involve the Government and private sector to understand the different conditions of the diseases and management of the patient.***

**Committee Response:** In respect of this prayer, the Committee noted that under the UHC Program, the MoH in collaboration with County Governments need to

develop a communication strategy to educate, raise awareness and promote awareness of autoimmune diseases amongst Kenyans.

Further, the Committee observed that the MoH, relevant health regulatory bodies and health worker associations should act to scale-up continuous medical education on autoimmune diseases like MS and NMO.

*12. Prayer Six: Intervenes for the undersigned group to obtain a proper cover under the National Hospital Insurance Fund (NHIF) like the case of cancer patients who get free drugs and chemotherapy; and*

**Committee Response:** In respect of this prayer, the Committee noted that NHIF only covers MS and NMO diseases in the benefits packages that it offers under its managed schemes e.g. Civil Servant Cover.

However, for patients on ordinary NHIF cover, the benefit package is limited to dialysis, or procedures currently covered under the national scheme. This has left patients with MS and NMO unable to access needed treatment, and exposed them to catastrophic health expenditure.

The Committee further noted that unlike cancer patients who had been granted access to drugs and chemotherapy under NHIF, no special provision had been made for patients with MS/NMO. This was in itself discriminatory. To address this, the Committee observed that NHIF should develop a special cover for patients with MS/NMO aimed at ensuring that they receive the highest attainable standards of care in line with Article 43 of the Constitution, without incurring catastrophic health expenditure.

In light of the above, the Committee resolved that:

4. This report be dispatched to the Ministry of Health for purposes of reporting back to the Senate on the progress it has made in respect of: ensuring the prioritization and procurement of DMDs for the management and care of patients with MS/NMO at all public health facilities through KEMSA; scaling-up the availability of Specialist care; facilitating assessment processes for patients with MS/NMO for purposes of the providing for the early detection, recognition, mitigation and socio-economic relief of patients suffering from the debilitating effects of MS/NMO before they progress to actual disability; and, scaling up

public awareness and continuous medical education on autoimmune diseases like MS/NMO within **six months** receipt of this report.

5. This report be dispatched to the National Health Insurance Fund (NHIF) for purposes of developing and rolling out a special cover for patients with MS/NMO within a period of **six months**. This cover should be aimed at ensuring that patients with MS/NMO receive the highest attainable standards of care in line with Article 43 of the Constitution, without incurring catastrophic health expenditure.
6. This report be dispatched to the National Council for Persons with Disabilities for purposes of proposing mechanisms for the development, and rolling-out of interventions for the early detection, mitigation, and socio-economic relief of patients suffering from the debilitating effects of MS/NMO before they progress to actual disability within a period of **six months**.

NEUROMYELITIS OPTICA (NMO) CONCERNING THE CHALLENGES FACED BY PATIENTS SUFFERING FROM MULTIPLE SCLEROSIS (MS) AND NEUROMYELITIS OPTICA (NMO)

[After the Order for Petitions is read, Sen. (Dr.) Isaac Mwaura, CBS, MP, will rise and present the petition before the House, pursuant to Standing Order 230(2)(a).

1. Honourable Senators, pursuant to standing order 231, I shall now allow comments, observations or clarifications in relation to the petition for not more than thirty minutes.

[after comments by Senators]

2. Honourable Senators, pursuant to standing order 232(1), the Petition should be committed to the relevant standing committee for its consideration. In this case, I direct that the Petition be committed to the Standing Committee on Health
3. In terms of standing order 232(2), the Committee is required, in not more than sixty calendar days from the time of reading the Prayer, to respond to the Petitioner by way of a Report addressed to the Petitioner, and laid on the Table of the Senate.
4. I thank you.

Hon. Speaker  
You may approve  
10/11/20  
Approved  
10/11/20

... arrangement  
- way a matter on the  
- subject (statement?)  
by establish ...  
2/11/20



Sen. (Dr.) Mwaura Maigua Isaac, CBS, MP  
(Senator for Persons with Disabilities)  
Speaker's Panel Member

advised on ...  
30 OCT 2020  
2021  
02.11.20

Parliament Buildings  
Tel: +254 20 2221 291  
P. O. Box 41842 - 00100 Nairobi, Kenya

K.I.C.C 2nd Flr. Rm. 206  
Mobile: +254 721 864 949  
Email: hon.mwauraooffice@gmail.com

THE SENATE  
RECEIVED  
02 NOV 2020  
DIRECTOR LEGISLATIVE AND  
PROCEDURAL SERVICES

SIM/OL/08/10/2020

26<sup>th</sup> Oct 2020

THE CLERK,  
THE SENATE,  
PARLIAMENT BUILDINGS,  
P.O. BOX 41842 - 00100  
NAIROBI

③ Ms. Macharia.  
Please see (B) and  
facilitate the petition.  
D. Chandra -  
03/11/2020.

DLPS  
Please facilitate  
DC(MA)  
Date: 2/11/20

Dear Sir,

RE: PETITION TO THE SENATE CONCERNING CHALLENGES FACING  
PATIENTS SUFFERING FROM MULTIPLE SCLEROSIS (MS), AND NEUROMYELITIS  
OPTICA.

We, the undersigned, citizens of Kenya AND in particular Multiple Sclerosis (MS) and  
Neuromyelitis Optica (NMO) transplant survivors and families,

Multiple Sclerosis is a disease in which the immune system eats away at the protective covering  
of nerves, resulting nerve damage disrupting communication between the brain and the body.

Neuromyelitis Optica spectrum disorder (NMOSD), also known as Devic disease, is a chronic  
disorder of the brain and spinal cord dominated by inflammation of the optic nerve (optic  
neuritis) and inflammation of the spinal cord (myelitis).

Draws the attention of the Senate to the following:

THAT, Multiple sclerosis, or simply MS, is a rare autoimmune disease that causes the body's  
own defences to destroy neurons in the brain and spinal cord.

THAT, Neuromyelitis optica spectrum disorder (NMOSD), or simply NMO also known as  
Devic disease, is a chronic disorder of the brain and spinal cord dominated by inflammation of  
the optic nerve (optic neuritis) and inflammation of the spinal cord (myelitis).

PETITION TO THE SENATE CONCERNING CHALLENGES FACING PATIENTS SUFFERING FROM  
MULTIPLE SCLEROSIS (MS), AND NEUROMYELITIS OPTICA.

THAT, both NMO and MS are debilitating diseases because they affect the nerves. When you suffer from MS or NMO, the body destroys myelin, the fatty insulating material that covers the nerve fibres that form part of the nervous system, which controls all bodily functions.

THAT, demyelinated nerves cannot transmit impulses to the brain or spinal cord and from the muscles in the body. Consequently MS/ NMO patients sometimes have difficulty with simple things like swallowing food, blinking, vague vision, controlling their bladder or limbs, or focusing their eyes on an object.

FURTHER, Symptoms of MS depends on which part of the nervous system is targeted. Common problems may include fatigue, continence problems, sexual problems, constipation, pain, cognitive (thought-related) changes, altered sensation, and muscular and visual changes.

THAT, a person with MS or NMO may struggle to come to terms with their disease. They might fear for their future or suffer from low self-esteem because of the physical changes they are experiencing.

FURTHER, MS can target virtually any part of the nervous system. It can affect the nerves of the reproductive organs, which leads to changes in sexual functioning. Slowed arousal time, reduced libido or desire, and altered or gastric response are not uncommon experiences.

THAT, the growing burden of MS and NMO diseases has been raised as one of the most significant barriers to the attainment of the Universal Health care (UHC).

THAT, in the line with the big four agenda-universal health care, NHIF does not provide cover MS cases, most patients end up as people living with disability.

THAT, we have made the best efforts to have these matters addressed by the relevant authorities all of which have failed to give a satisfactory response.

THAT, none of these issues raised in this Petition is pending in any court of Law, Constitutional or any other legal body.

THEREFORE, your humble petitioners pray that the Senate investigates this matter and -

1. Initiates the subsidy of the price of medicine to a more affordable price. A DMD ( disease modifying drug) or weekly Injections can go to as high as 100,000 KSH.
2. Intervenes in the matter with a view to ensure that <sup>there</sup> are more and qualified specialists in all hospitals especially districts hospitals. MS and NMO resemble several other autoimmune diseases. A pin point diagnosis would help management of the disease, before one gets to the progressive stage of the disease, which is rarely manageable.

PETITION TO THE SENATE CONCERNING CHALLENGES FACING PATIENTS SUFFERING FROM

disease, before one gets to the progressive stage of the disease, which is rarely manageable.

3. Initiates the recognition of this group as a group of people living with disability and therefore be exempted on taxation.
4. Initiates free counseling and therapy services
5. Initiates the process funds allocation to carry awareness campaigns that will involve the government and private sector to understand the different conditions of the diseases and management of patients affected.
6. Intervenes for the group to obtain a proper <sup>to extend</sup> cover the underserved group under the NHIF like the case of cancer patients who get free drugs and chemotherapy;

Dated this 26<sup>th</sup> day of Oct 2020.

NO.	NAME	ID	SIGNATURE
1	Miriam Juma	24922746	Juma
2	Fackline Makani	24901834	Makani
3	Lucia NDOLO	2626590	Ndolo
4	Alexander Nyula	3506353	Nyula

Counter signed by Senator (Dr.) Isaac Mwaura, CBS, MP.



Sen. (Dr.) Isaac Mwaura, CBS, MP,

PETITION TO THE SENATE CONCERNING CHALLENGES FACING PATIENTS SUFFERING FROM MULTIPLE SCLEROSIS (MS), AND NEUROMYELITIS OPTICA.

