

P.O. BOX 41842 - 00100 **NAIROBI**

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).

THAT, both NMO and MS are debilitating diseases because they affects 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 organic 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 they 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.

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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.

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6. Intervenes for the group to obtain a proper cover the undersigned group under the NHIF like the case of cancer patients who get free drugs and chemotherapy;

Dated this 26^{th} day of 0.0 2020.

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

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