

## INTERNAL MEMO

REF EALA/MEM/11

TO Chairperson

Committee on General Purpose

CC Hon. Speaker, SCA - GP

FROM Clerk

DATE February 03, 2016

**SUBJECT** PETITION BY THE ALBINSIM SOCIETY OF KENYA TO

THE EAST AFRICAN LEGISLATIVE ASSEMBLY (EALA) TO ADVOCATE FOR THE PROTECTION OF PERSONS WITH

**ALBINISM** 

Attached herewith please find a Petition from Albinism Society of Kenya.

The purpose of this Memo is to forward to you the above mentioned Petition for consideration by your Committee.

Kenneth Madete

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Albinism Society of Kenya leterand
Improving the quality of life for persons with Albinism

PETTITION BY THE ALBINISM SOCIETY OF KENYA TO THE EAST AFRICAN LEGISLATIVE ASSEMBLY (EALA) TO ADVOCATE FOR THE PROTECTION OF PERSONS WITH ALBINISM.

## INTRODUCTION TO ALBINISM.

Albinism is a condition that results from genetic mutations that causes little or no pigmentation in the eyes, skin or hair. Melanin is responsible for eye, skin and hair colour. Without sufficient melanin, the eye is unable to function properly and its nerve connections to the brain are also altered. Therefore most people with albinism have very pale skin, hair and eyes and are often characterized by long- sleeved clothing, hats and dark glasses as a measure against the sun. Albinism can affect all races

## 1.0 BACKGROUND

There is no official data that provides for the exact number of persons with albinism to ascertain the exact population in East Africa. However studies reveal that the frequency of albinism worldwide is estimated to be approximately 1 in 20,000 in most populations, 1:17-20,000 people within the Caucasian race, Tanzania at a ratio of 1:4,000. There is therefore the need of a regional database for persons with albinism in the wider East African region, given as per each country's head count in order to ascertain the exact numbers.

The Integration process is a reality but is also an aspirational and progressive goal. For the fruits of integration to be enjoyed by all citizens and as such it is important that the EALA take the albinism protection cry in the integration Agenda..

The albinism fraternity in EALA member nations recognize efforts made by State parties and civil societies to address the insecurity of persons with albinism posed by the widening illegal market for their body parts which has been instigated by myths, misconceptions and

There is need therefor for laws that protect the social, educational, cultural and spiritual needs of persons with albinism so as to realise a smooth integration of the EAC..

## PETTITION TO THE EALA 3.0

NEED FOR EXTENDED AWARENESS; PWAs are discriminated in our communities based on cultural practices and beliefs that do not support social inclusion. They are often segregated from the community and are denied their rights. They are at a high risk of being trafficked due to the myths and misconceptions that their body parts are

a source of wealth and good charms. The EALA need to enact laws that promotes albinism awareness in the entire region.

- APPREHENDING PERPETRATORS OF PWA KILLINGS: Many persons with albinism in East Africa have fallen victim to the ritual killings that are based on the misconceptions of them being a source of good luck. Even with the strict trafficking laws in the EAC member countries, the market for PWAs body parts has widened. Sadly these crimes are perpetuated by close associates to the victims. Our prayer is that the EALA stipulates stiff penalties in the new law that will amount to death penalties or life imprisonment to the perpetrators of PWA killings.
- ECONOMIC EMPOWERMENT OF PWAs; in assisting Persons with Albinism develop a positive self-image in order to exploit their full potential in education, social and economic activities there is need for economic empowerment. Keeping PWAs in rescue centers for an extended time only increases stigmatization and demeaning integration in the process. There is therefore need for the EALA to come up with Africa.
- EDUCATION; Lack of melanin in the eye causes low vision to persons with albinism
  with variance from one individual to another. This therefor affects the extent of their
  sight as far as education is concerned. To propagate inclusion in the education
  sector. Learners with albinism require prescription devices to cope with education the
  regular setting. Member states should support PWAs education by subsidizING
  funding for school fees and eyecare support services.
- HEALTHCARE; In order to protect persons with albinism from skin cancer (the
  deadliest killer disease for PWAs) there is need for a comprehensive healthcare
  program which entails FREE provision of sunscreen lotions, after sun and lipcare
  products, protective clothing and frequent skin screening services at affordable cost.
- EMPLOYMENT: Many employers discriminate against PWAs for employment
  positions siting their disability. This has continually been practiced despite the
  academic credentials and experience of many PWAs showing that they are
  competitive. The EALA should come up with an affirmative action seeking inclusion
  of PWAs in the job market and penalizing employers who don't heed.

We believe that if this petition by 3,000 PWAs in Keya should be considered as a matter of urgency for the benefit of all PWAs in the East African region.

HON. ISAAC M MWAURA MP.

COLLINS OMBAJO

CAROL MARETE OFFICIAL.