

## **PLIGHT OF PERSONS LIVING WITH ALBINISM IN KENYA**

Little information is available on the situation of PWAs in Kenya. There are no accurate estimates of the number of people living with the condition and little systematic research has been undertaken in Kenya to identify the full range of obstacles and disadvantages, arising in part because of prejudice and superstition and in part as a result of failure by the government and other duty bearers to make reasonable commitments to recognize and address the needs of PWAs especially the health and social needs.

In August 2010, Esther Moraa, a Kenyan child born with albinism was killed by her mother. The mother claimed that her husband had convinced her to kill the baby since she was born with albinism and hence a bad omen and a disgrace to the family. She was jailed for one year but her husband remains at large. Source: Under the same Sun on internet.

August, 2012 a Kenyan man, Nathan Mutei, was sentenced to 17 years in prison in Tanzania and a fine after confessing to human trafficking. He was arrested while trying to sell Mr. Wanjala from Kitale, Kenya, a man with albinism to undercover police officers posing as businessmen.

December 24, 2010:

A three weeks old baby boy with albinism was killed by his mother because the father was threatening divorce saying that the baby was a ghost and not his offspring.

Source: Citizen Television, Kenya

The most recent survivor: Friday, March 15, 2013

A seven year old boy with albinism in Embu, Kenya managed to escape relatives (uncle) who tried to sell him for ritual purposes. He was kidnapped by his uncle together with other relatives who attempted to take off to an unknown destination where they were to meet the buyers. The boy said that the kidnappers threw him out of the window of a moving vehicle when he screamed. (Source: Citizen News, March 15, 2013; by Patricia Wambui)

### **Discrimination and Stigma against PWAs in Kenya**

Due to misconceptions and myths, persons with albinism in many parts of Kenya face stigma and discrimination right from birth and in their day to day lives. Discrimination infringes on their fundamental human rights and basic freedoms. Various forms of discrimination and abuses/violations include:

#### **I) Social stigma and derogatory name-calling leading to prejudice and discrimination:**

In Kenya, PWAs stand out because they are white in a black community. They are largely seen as being alien incomplete and lesser beings as if they are incomplete. They are referred to derogatory names for them has led to prejudice and stereotypes which lead communities to condemn them based on the condition rather than appreciate their humanity first. Most of the descriptive terms used to refer to persons with the condition are derogatory and demeaning. They seem to suggest a lesser being. In Kiswahili, a national language in Kenya, different

communities have names they use in reference to PWA's all of them derogatory. In the course of working with PWAs AFEA has come across names among others

*'Ngojiro'* meaning *ghostly and ugly creature at the coast of Kenya* *Zeru Zeru* meaning 'ghost like creature'

'Pesa' Kiswahili word for money is currently a common reference to PWAs since the revelations coming from Tanzania of the trade in Albino body parts

'Mzungu' meaning 'white man' across the country

'Muthende' a Kikuyu name referring to one as a half naked boy of the village. This was a name given to the only boy with albinism in the village by his peers in elementary school.

All these references lead to discrimination based on color difference

With regard to marriage and the right to found a family, PWAs have been treated with stigma for generations. Whereas people who are pigmented find it relatively easy to find partners, those with albinism are routinely forced to lead their lives single because no one wants them or families refuse to sanction relationships. They suffer rejection by the community

Around 2009 Jennifer a mother of a three year old from Kisauni Mombasa was deserted by her husband upon giving birth to the beautiful girl. She has not seen him since

Teenage mothers single

Mama Afid from Old Town Mombasa is bringing up a boy currently in class 8 elementary school that was abandoned by his parents at his early age

Ms x gave birth to a child in Mombasa Hospital in February 2013. She refused to accept the child with albinism as hers and disappeared living the in infant in the hospital. It took AFEA's and the hospital counseling to get her to collect the baby.

## **ii) Gender-based sexual violence**

The myth that having sex with a woman with albinism can cure HIV/AIDS has fueled this form of violence. Omollo Lucy Anne, a 23 years old lady with albinism in Nairobi has twice met both young and old those have seduced her in the hope and believe of getting healed from HIV/AIDS

"Most of them are married men, and when I asked every one of them for the HIV test they feared and run off" she explained.

AFEA works with hundreds of women Parents of Children with Albinism (PCWA) that have suffered domestic violence because they gave birth to children with albinism. This has been from their husbands and extended family and communities they live in.

Apart from physical violence they suffer psychological and mental torture from insults and isolation.

### iii) Killings and harvesting of body organs:

In the past, most societies in Africa practiced infanticide on infants that were considered undesirable including those with disability, children with albinism and circumstantial episodes of twins. Although many societies have ceased the practice, it is believed some communities still continue this culture. According to the Managing Trustee of AFEA “ I have travelled and worked in all districts in this country. I have never seen a PWA in most of them. Does it mean they are not born? Could the old age tradition of infanticide still be alive?” Handbook on Constitutional and Legal Rights of persons with Albinism, Dec.2012

In Kenya, most parents, families and communities have been at pains to explain the condition when a child with albinism is born. It is this kind of stigma that led to the killing of Esther Moraa, a Kenyan child born with albinism by her mother in August 2010. In court, the mother claimed that her husband had convinced her to kill the baby since she was born with albinism and hence a bad omen and a disgrace to the family. She was jailed for one year but her husband remains at large.

Source; Internet Article by Muthee Thuku on internet February 2011

### v) Lack of appropriate medical attention:

The biggest challenge to PWAs in Kenya besides discrimination and stigma is the risk to Skin Cancer. AFEA has known 17 cases of cancer in the last 3 year 5 of whom have since died. There are only a couple of cancer screening machines in the country, majority of PWAs do not seek medical help in time and many have yet to know how to protect themselves and worse still afford protective items as sunscreen. Although some 200 million Kenya shillings has been set aside for this purpose, incompetence in the respective duty bearers has resulted in the sunscreen not being provided yet.

In Kenya health care for PWAs is very poor because the condition has not been seen as a true health concern. The government and the health structure do not provide PWAs with sun glasses, sunscreen lotions, special low vision aids, making it almost impossible for a person living with albinism to spend much time outdoors. When a PWA falls sick, be it minor or major, they are not given proper medical attention in that they are very delicate so cannot be injected or stitched as experienced below by Wafula Stephen Marango.

“I remember in the year 2005 early morning, I decided to clean our home compound using a panga (cutting grass). I accidentally cut my left thumb deeply and it was bleeding badly. Luckily the hospital was nearby. My brother, who was rushing for a class, washed my hand and wrapped a cloth round it. At the hospital, the nurse refused to stitch my wound saying that **my skin was too light** and suggested they cut off my finger. I refused and demanded they stitch it or I call my father, who was working a few meters away in another department. I held my wounded hand up and she did stitch. Right now the finger I would have cut is functioning very well, and I always smile seeing it, because it tells a story-like this.”-Wafula Stephen Marango-Accountant Albinism Foundation of East Africa

In the case of work AFEA has been informed by not less than 10 people that they were denied the chance to donate blood by paramedics because their blood is either ‘unacceptable’ ‘suitable’

or they 'could not withstand the operation due to their fragility'. For these and other fabled reasons, John Onchoke a primary school teacher in Kisii confessed in a recent May 2013 AFEA workshop that it was the first time he had heard that the reality is that PWAs could donate blood

"I had always believed that PWAs could not donate blood... that it is different blood from other people"

Youth with albinism have been denied their cultural rights of passage which in some societies require men circumcision e.g. In Kisii youth with albinism are forced to resort to medical practitioners to carry out the operation because traditional circumcisers would refuse to carry out the operation.

In the cause of working with PWAs since 2008 AFEA known 17 people with cancer of the skin five of whom have since died

#### **v) Discrimination in employment**

Persons with albinism are routinely shunned from employment by both private employers and government sector due to their condition. They are thought of as being incapable or as being a burden. Sometimes, they are employed but assigned tasks that require them to work for a long time in the sun which exposes them to the risk of developing skin cancer. The condition also causes sight impairments which mean that most PWAs cannot pass the vision component of a driving test yet some employers invariably request driver's licenses even when such a criterion might not be necessary to fulfill the post. Also PWAs, even when qualified, are routinely discriminated against. As in the case Omollo Lucy Anne:

*"In February, 2012 I was called for a job interview at Transmara Sugar Company in Kenya, for the position of Human Resource Assistant. After the interview, the manger pointed at me among others then said, 'you lady! I just wanted to see how you are looking like when I saw your passport in the application letter, I never new people like you can pursue HRM.'"I looked at him in the eye, gave him a plastic smile then walked away very unhappy".*

#### **vi) Discrimination in education system**

For years, Kenya have put students with albinism under the same conditions as other students without taking into account the visual impairment associated with the condition. In other instances, students with albinism are taken to schools for the blind while they are not blind. Poor vision may cause students with albinism to be slow learners either due to inability to see the black board clearly or inability to read books and other learning materials.

The colors used in writing also matter because students with albinism have a problem with contrast. The text books and exam papers are mostly printed in normal fonts which may be hard for students with albinism to read quickly. Persons with albinism have a medical condition known as nystagmus or pendulous nystagmus. It sometimes makes the words wiggle on the page and makes it hard to focus on small narrow print.

Students with albinism have also been required to finish exams at the same time as other pigmented students whose sight is normal. These conditions have led to poor academic

performances and low education levels for persons with albinism. This in turn denies them livelihood options hence the abject poverty that many live in. Lack of education and life skills also limits their active participation in local, national and international affairs. Mumbi Ngugi of Albinism Foundation of East Africa writes:

*'We have to battle skin cancer because we do not have melanin, yet most of us cannot get adequate education, and even if we do, getting employment is a major challenge. So we end up working in the sun, as farmers or hawkers, and die before our 30th birthday.'*

### **vii) Attacks on persons protecting/defending persons with albinism**

Many parents of children with albinism, especially mothers are usually attacked and frustrated when protecting their children against the denial of their right to life.

### **viii) Divorcing mothers of children with albinism**

Many women have been divorced by their husbands and shunned by families after giving birth to children with albinism. They have been accused of sleeping with men of other races; of being cursed and unclean; and of being witches. Children with albinism have also been hidden from the public, forbidden from socializing with others and treated as outcast. In the year 2012, AFEA did a rapid study on the extent of marginalization of women with and affected by albinism where it was realized that many women and children are abandoned or divorced after birth. As seen in the Jane's story, a woman who gave birth to a baby boy with albinism.

*Jane, a MCWA was shocked at giving birth to a CWA since she had never seen any PWA before. When her mother in law learnt that Jane had given birth to a CWA, she never touched or went to see her daughter in law for the 3 days she was in hospital. She has never touched the child until today. Jane's mother in law advised Jane's husband that, in their family, they never give birth to such children hence Jane should be divorced. Due to pressure from his family, the husband ran away from the family for three years.*

*Jane's maternal relatives had several relations living with Albinism hence her father readily advised her and offered every support i.e. emotionally, financially and every other support she needed to take care of her CWA. Otherwise, all the relatives, friend and neighbors shunned her away. Even those who used to fetch water from her home stopped fetching it from there. They believed in myths like that when they cross over her urine or associate with her in any way, they may also end up giving birth to CWA. The doctors in the hospital spoke negatively about her CWA and this further demoralized her. Her own daughter in law divorced her son after being incited by the community that she will also give birth to child with albinism.*

*Jane stopped working in order to take care of her CWA as everybody refused to take care of him. She also feared people might hurt because they hated him so much. Earlier on, Jane did not take her child out because she feared criticism from the people but today, she is so proud of him and she is doing everything necessary to take care of him.*

*(SEE ATTACHED REPORT)*

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## **WHAT THE GOVERNMENT OF KENYA HAS DONE FOR PWAs**

Only in the last 2 years has the government started to show interest in albinism through:

1. Recognition of albinism as a disability
2. For the first time in history in Kenya the government has provided some funds to directly benefit PWAs. This was after AFEA in conjunction with Kituo Cha Sheria and people with albinism themselves lobbied and led a delegation to parliament to demand for a budget to be set aside in the national budget to cater for sunscreen and cancer screening machines. In the supplementary budget of 2011/2012 a total of Kenya shillings 150 million was budgeted and provided for that service.

For 2013/2014 financial year, the GOK has allocated Ksh. 100 000 000 for PWAs program, The NCPWD is going on with the census of PWAs in Kenya.

3. The constitution of Kenya has provided for people with disability special rights according to Article 54 on Rights of People with Disability (PWAs included)

-Dignified treatment

-Access to places, education facilities, institutions, integration, materials and devices to overcome constraints arising from disability

Progressive implementation 5 % rule on elective/appointive positions are for Persons with Disabilities (PWDs)