



## ENGAGE NOW AFRICA

### REGIONAL ACTION PLAN ON ALBINISM IN AFRICA (RAP)

#### IMPLEMENTATION REPORT

#### INTRODUCTION AND OVERVIEW OF ALBINISM IN GHANA



Figure 1; Section of PWAs at a Sensitization Durbar at Bruhani Ghana

In some communities in Ghana and Africa as a whole, erroneous beliefs and myths, heavily influenced by superstition, put the security and lives of Persons with Albinism (PWAs) at constant risk. These beliefs and myths are centuries old and are present in cultural attitudes and practices around the world. Some of these

beliefs and myths includes; Persons with albinism are regarded as ghosts and not human beings. In some countries including Ghana, they are considered to simply vanish. They are seen as devils or persons suffering from a curse or a sort of punishment to their family. it is believed that contact with them will bring bad luck, sickness or death.

Persons with Albinism are object of public ridicule, discrimination, and stigmatization coupled with superstitious cultural beliefs in Ghana. These acts of inhumanity on such individuals make them feel as a social outcast hence prevent them from active engagement in their various communities'



Figure 2; Fracisca (With Albinism) playing with other children

activities. Many PWAs are neglected by their own families, drop out of school and even go into hiding because of the fear and humiliation they experience in their communities. These make them develop low self-esteem and lack the confidence to participate in activities within



Figure 3; Round Table Discussion between Engage Now Africa and Ghana Association of Persons with Albinism At ENA Office

their communities. The situation is worse when it comes to the area of relationships and marriage. Families reject PWAs and in situation of a child born with albinism, the mother and child suffer abuse and rejection from family members and sometimes their spouses.

On daily basis, PWAs encounter heckling on the street not only

from children but adult alike. Prejudicial statements are common about albinism both in the media and general public. Employers see persons with albinism as those with no requisite skills and moreover as those who can only scare away potential customers and therefore shun away from engaging them in any kind of employment especially in the private sector. As a result, most PWAs who are gainfully employed are those engaged by government institutions.

A research survey conducted by Ghana Association of Persons with Albinism came out with the following findings on customary banishment of persons with albinism in Ghana.

1. The research showed that the prevalence of the custom of ritual banishment of PWAs in Kwahu Bokuruwa in the Kwahu East district of the Eastern Region of Ghana
2. That, there exist prevalence of the custom of ritual banishment of PWAs in Akwamufie in the Asuogyaman District of the Eastern Region of Ghana
3. That, there exist prevalence of the custom of ritual banishment of PWAs in Abease in the Prang District of the Bono East Region of Ghana.
4. That, in all the three communities, the custom originated from the ritual sacrifices to local gods, namely *Ajokrofi*, (in the case of Abease), *Oku Abena*, (in the case of Bokuruwa), and the god *Tutu-Aba*, in the case of Akwamufie,
5. That, there are other Ghanaian communities with similar practices, these include
  - Akango, in the Ellembele District (Western Region),
  - Dawu and Awukugua in the Okere District (Eastern Region),
  - Larteh Akonedi Shrine and parts of Akropong, in the Akuapem North District (Eastern Region),

- Kani, a town in the Upper West Region etc.

Based on these research findings, the Association in collaboration with Engage Now Africa petitioned the Commission for Human Rights and Administrative Justice on the occasion of the 2019 International Albinism Awareness Day held at the British Council Auditorium in Accra on the 13<sup>th</sup> June 2019.

## **ABOUT ENA’S ALBINISM PROJECT**

### **VISION**

To eliminate the myths associated with albinism worldwide and to increase self-confidence and instill hope in the minds of persons with albinism for greater achievement.

### **OBJECTIVES**

The objectives of the project include:

1. Create an inclusive society free of discrimination, stigmatization and total elimination of myths and misconceptions associated with albinism worldwide.
2. Promote and protect the fundamental human rights of persons with albinism.
3. Instill hope, create opportunities and increase self-confidence and self-esteem among persons with albinism.

### **Overview of ENA’s Albinism Project**



*Figure 4; Albinism Project Team Members From Left Francis Yaw Ansah (Education Director), Sylvia M Ansah (Albinism Project Coordinator), Rejoice Ziwu (Assistant Albinism Project Coordinator) and Kwame Andrews Daklo (Albinism Programs Coordinator)*

In 2016, Engage Now Africa took up the mantle to educate and sensitize Ghanaians on albinism through community sensitization activities and also provide help to persons with albinism through medical supports, educational scholarships and skills training. The ENA Albinism Project is aimed at eliminating

myths associated with the condition while boosting the confidence level of persons with albinism.



Since 2016, ENA has organized sensitization durbars in 9 out of 16 regions in Ghana including 17 community-based sensitization durbars, 8 schools-based sensitization program, one regional forum on albinism and also organized three of the International Albinism Awareness Day (IAAD). In all ENA has educated and sensitized about 20,000+ people on albinism and impacted the lives of 200,000+ people nationwide and beyond. 500+ persons with albinism have benefited from ENA's activities including sunscreen lotions, wide brimmed hats, sunglasses, long sleeve shirt among others. We are supporting 15 PWAs in education, 5 in petty trading and apprenticeship and 4 skin cancer patients. To prevent skin cancer and its related deaths among persons with albinism, ENA and its partners have developed sunscreen from local available materials (Shea Butter) and have also employed PWAs in the production of this cheap product called Mela-Protects Sunscreen.

### **Public Education and Awareness Creation**



*Figure 5; Cross section of a community sensitization durbar at Naabu, a border community in Nkwanta North District of Oti Region Ghana*

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and impacted the lives of 200,000+ people nationwide and beyond. 500+ persons with albinism have benefited and learnt about their own condition during community and school sensitization activities organized by ENA. Aside these one on one engagements, ENA have also involved the use of the traditional and social media in its awareness creation activities on albinism. TV and radio sensitization activities are targeted at the urban dwellers whiles the community durbars are meant to reach communities with identified cultural practices that discriminate or stigmatize against persons with albinism.

Information flyers with adequate information on albinism were developed and distributed among the participants of these durbars and events. Since 2017, ENA have adopted the international Albinism Awareness Day and made it a major national even on albinism where major policy issues are discussed in a forum.



Figure 6; Group photo of participants of a community sensitization at Moree, a fishing community in Central Region. Ghana

The IAAD forum rotate from one

region to the other with the aim to reach many people with the education and awareness on albinism on a national base. During these fora, PWAs in around the target communities are given the opportunity to share their life experience with regards to discrimination and other practices that infringes on their fundamental human rights. Engage Now Africa has also produced a short film on the struggle of persons with albinism in Ghana. This short film is occasionally being televised to sensitize Ghanaian and expose to the general public such attitudes that hinder personal development of individuals with albinism. The film also forms part of the yearly international albinism awareness day celebrations.

### **Gender Dimensions/Children with Albinism**



Figure 7; Group photo of single mothers of children with albinism in Aflao, Volta Region Ghana

Women and girls with albinism as well as mothers of persons with albinism have been particularly affected by stigma and discrimination of various forms. Many women with albinism are either single mothers or have remain unmarried due to stigma, discrimination and rejection from families. Girls with albinism are victims of abuse physically, psychologically and emotionally in the house, society and in school environment.

Engage Now Africa through its work have been able to identify and rescued 4 mothers of children with albinism who suffered banishment and rejection from their husbands, family and community. These women and their children have received support from the organization to resettle while their children with albinism are now under the care of the organization for educational supports and scholarships. The mothers have also been setup with businesses of their choice to make them self-reliant. With regards to women and girls with albinism, we ensure that they benefit from our support systems in term of protective gear including sunscreen, long sleeve shirts, wide-brimmed hats and sunglasses. Supports and assistance are provided to girls in their education while others are made to learn skills through apprenticeship. Currently 8 girls at various stages of their education from KG to first degree level are benefiting from ENA's educational support system while 4 women have received startup funds to run their businesses and skill acquisition.

## Health



*Figure 8; skin cancer patient receiving radiotherapy treatment at Sweden Ghana Medical Center. Accra Ghana*

Skin Cancer is the main challenge persons with albinism face in Ghana. Managing skin cancers among Persons with Albinism in countries like Ghana where there are a lot of myths surrounding albinism poses major therapeutic challenges. The worst of it all is that persons with albinism are not always given adequate attention when they visit the hospitals for treatment. Late

presentation with advanced lesion coupled with lack of therapeutic facilities such as radiotherapy services are among the hallmarks of the disease in Ghana. The outcome of treatment of skin cancers among Persons with Albinism in Ghana has always been sad because the majority of these patients present late to the hospital with advanced stage. This is partly due to paucity of local data regarding this condition and lack of community awareness on the danger of skin cancer to Persons with Albinism. It is also due to the inability of persons with albinism to afford the cost of skin cancer treatment. As a result, many died from skin cancer related complications. There is total lack of government support toward skin cancer victim coupled with the level of poverty existing among such individuals and their families.



Engage Now Africa since the initiation of the albinism project took it upon itself to provide support to cancer patients. Since 2017, we have supported 4 skin cancer patients whose cases were at the advanced stages at the time of their discovery by the organization. In our quest to prevent instead of spending on surgery, radiotherapy and chemotherapy, we provide sunscreen lotions and creams to persons with albinism we work with. We also provide long sleeve shirts, wide brimmed hats and sunglasses

Procuring sunscreens in Ghana has been very challenging partly due to its unavailability and partly due to its cost. For the past two years, ENA has provided over 2000 bottles of sunscreens to over 500 persons with albinism over the two



Figure 9; Mela Protect sunscreen produce from Ghana By Engage Now Africa

years of operating in the albinism community. Due to the widespread and nature of our programming, we have attracted the attention of group of chemists from the Brno University of Technology (BUT) Faculty of Chemistry (Czech Republic) who through partnership have develop sunscreen locally with the use of readily available shea butter in Ghana. This product is currently being used by some persons with albinism in Accra and its environs, while few has been sent to Nigeria and Sierra Leone. Extensive work is being done on the distribution of the cream to reach as many people as we can. The cream project is meant to end or reduce the rate of skin cancer among persons with albinism in West Africa in the next 5-year. We are also looking at employing a good number of persons with albinism in the production and distribution chain of the cream.



Figure 10; Mela Protect sunscreen produce from Ghana By Engage Now Africa

## Data Collection

Data is key to the Accountability Measures of the Regional Action Plan on Albinism. To this end, Engage Now Africa has developed a basic data collection tool which is use on the field during the sensitization durbars to collect essential data on persons with albinism attending our program. This basic data is use by the organization in tracking Education, health and other essentials of persons with albinism. It is through this data that we are able to determine who to provide help to in term of education, health or skills training. We are also working on getting persons with albinism counted during the 2020 national census to be conducted by the Ghana Statistical Services.

## Conclusion

At Engage Now Africa, we are determined to change the narrative on albinism through public education and community sensitizations programs and activities. We are creating opportunities and developing the capacities of PWAs to excel and engage in the developmental agenda of their various communities. Our activities and program such as Mela Protect Sunscreen project and skin cancer Campaign are meant to solve the skin cancer problem among PWAs by reducing the death related to this health challenge while providing sustainable employment and healthy living among them. Engage Now Africa is working with various governmental institution on various policies to improve on the lives of PWAs in Ghana.



Figure 11; Group photo of PWAs with hospital items to be donated to Tamale West Hospital in Northern Region of Ghana