



## ANNUAL REPORT 2017



ALBINISM UMBRELLA  
PLOT 189 NAMULI ROAD  
P.O. Box 3262 KAMPALA  
[www.albinismumbrella.com](http://www.albinismumbrella.com)  
Facebook. facebook.com/albinismumbrella  
Twitter: @albinismumbrell

## **Background**

Albinism Umbrella is a voluntary, non-profit, nonpartisan and Non-Governmental organization that consists of human rights sympathizers, people living with albinism and all other albinism well-wishers. Albinism Umbrella (AU) was set up with the ultimate aim of having a joint voice for all persons living with albinism in Uganda.

It was established to engage communities of persons living with albinism and harmonize discrimination and stigma in their different communities. It further aims to empower persons with albinism to fully engage in social-economic activities that directly improves their living conditions.

## **Vision**

A society where persons with albinism (PWA) are fully engaged in every human activity and economically sustainable.

## **Mission**

To actively lobby and educate for PWA inclusion and their families on the global forum for sustainable development.

## **Tag line - Hope restored**

## **Objectives.**

1. To be an albinism voice in different forums on issues of albinism member's development.
2. To spear head research on the topic of albinism with the interest of reaching out and sensitizing the persons with albinism, their families and their community
3. To create a data centre of PWA, to actively advocate and lobby for the rights of such persons and their families at all level of administration and governance.
4. To create awareness of the socio-economic challenges that are faced by persons with albinism and to empower them to find their rightful places in society.

## **Our core values**

- Respectful
- Team work
- Professionalism
- Integrity

## **Prevailing situation**

Albinism is a genetic condition that is manifested at birth where one completely lacks or partially lacks melanin with evidence of pale or ash grey eyes, no color in hair and the skin. Albinism affects people from all races and ethnic groups over the world. The condition affects an estimated 1 in 17,000 people globally. In sub-Saharan Africa, the rate of albinism is around 1 in 5,000. (University of Illinois Sept 2016)

The main challenges faced by Persons living with Albinism (PWA) include: Skin cancer, stigma, derogative name calling, discrimination, denied employment opportunities and inhumane practices including ritual sacrifice. Most PWA have low levels of education due to the low vision, poverty and ignorance. Moreover, most PWA are often raised by single mothers having been abandoned by the fathers due to ignorance of the condition considering it as a bad omen. Poor access to information particularly in the rural areas regarding albinism, its causes and effects, precautionary measures against burns and skin cancer is a major concern.

PWAs have limited legal access because the laws of Uganda do not specifically include PWAs as a discriminated minority group. This poses further difficulties in their plight to secure the basic human rights to non-discrimination, equality, liberty, life and security because Article 32 of the constitution provides for 'groups marginalized on the basis of gender, age, disability, or any other reason created by history' which excludes PWA. There is no information on the total population and distribution of people living with albinism in Uganda. Very few PWAs are engaged in employment, formal or otherwise. There is also high level of illiteracy among the albinism community. Parents and children are often frustrated out of school due to low vision or at times denial to be admitted in certain schools.

## **ACCOMPLISHMENTS FOR THE YEAR**

Albinism Umbrella has four major areas that guide its operations. These include empowerment, sensitization, sunscreen production and the albinism center. AU strives to make a difference in the lives of PWA and their families through these areas of operation.

### **A. FUNDRAISING WALK FOR AN ALBINISM CENTER**

This is a **long term plan to have a center for PWA in Uganda.** The vision is mainly to **provide a location for skilling, empowerment and research center on albinism** matters. It is envisioned that different persons making a difference in the lives of PWA will meet, share experiences, and have a coordinated effort to reduce the levels of stigma and discrimination.

It should be emphasized that, **the center WILL NOT be an exclusive place for PWA.** We believe this would further discrimination. It is intended to be a place to showcase the untapped potential of PWAs. The center will however have a **small accommodation**

facility to house the distressed, homeless PWA to undergo counseling before returning to society.



***The albinism community at the very front with the Speaker of Parliament evidently enjoying the walk. What an awesome day it was!!!***

On February 5<sup>th</sup> 2017, the albinism community was privileged to start the first ever Parliament week. The Parliament of Uganda opened its doors to the public under the theme- People centered Parliament. This was the first time in 50 years of its existence to invite the public right up to its chambers.

On such a remarkable occasion, the albinism community shone so bright to open the long week activity packed event. Having the Rt Hon Speaker of Parliament flag off this walk was a demonstration of a people centered Parliament, not only to the forgotten, marginalized albinism community but to the entire country. Among the most interesting activities was this walk which was well attended by members of Parliament, corporate organizations, Government entities and individuals. A total of thirty-five millions (35M) towards the construction of the albinism center.

It should be noted that the session of people's parliament was equally interesting. Electing our own speaker, deputy speaker and having an order paper all done by the public in the Parliament chambers was a great demonstration of the operations of the August house to the masses. Meet your MP and touring the different departments of Parliament was



great sensitization for the masses. Many thought this huge structure was only occupied by MPs. Thanks to the Communication and Public Affairs department for the great work done.



*Artistic impression of the albinism center.*

### **Action points to follow.**

During her speech, the Speaker made some promises to the albinism community

- One vacancy at Parliament to be filled PWA as a demonstration to other employers as well as living the promise of a people centered Parliament
- She directed the Committee on Gender to bring out the human rights of PWA not be bundled up as the case now. PWA have unique needs that are not taken care of under the other rights
- To work with the albinism community for five years until the albinism center plan is fulfilled starting

### **B. EYE CLINIC**

The Rotary club of Nkumba in support with Rotary club of Lancaster USA carried out a free eye screening and provision of appropriate contact lenses. Albinism Umbrella was privileged to receive this much needed support. 60 PWA received free eye examination and two pairs of lenses each in February 2017. One pair as sun glasses while others for reading. The team provided transport from Kampala to Entebbe Hospital Grade B to these PWA.



***The team that offered the eye examination service.***



***Dr Bob McClenatha working on one of the beneficiaries.***

### C. INTERNATIONAL ALBINISM AWARENESS DAY JUNE 13<sup>TH</sup>

The United Nations Human Rights council adopted a resolution in 2013 calling for the prevention of attacks and discrimination against persons with albinism. June 13<sup>th</sup> was designated in 2014 and first celebrated in 2015. Since then, Albinism Umbrella has used this day to create awareness. This is a major activity in the year and we always look forward to such a meeting.

June 13<sup>th</sup> was under the theme “Advancing with renewed hope” and we created a sub theme “Embracing albinism as us”. Under this theme Albinism Umbrella sought different stakeholders especially the two main ministries of Education and Health.

We were privileged to have officials from the Ministry of Education headed by the Hon Minister of Sports, Hon Charles Bakabulindi. Several commissioners from the same ministry attended including Commissioner Mutekanga who pledged to work with us to increase albinism awareness in schools.

Other dignitaries in attendance include, Hon Sofia Nalule, Chairperson Equal Opportunity commission, Mrs, Sylvia Ntambi and the Head of the Office of Human Commission for Human Rights, i.e. Country Representative Dr. Uchenna Emeloye. We take the pleasure to sincerely appreciate Dr. Uchenna for the continued support each year. He has religiously attended each awareness day in person. We also received support from Under The Same Sun(UTSS), and Equal Opportunity Commission to successfully have this event.

In attendance were officials from the following organizations

- i. National Union of Disabled Persons (NUDIPU)- Youth representatives Sarah Namatovu
- ii. GALZ forum international Executive Director, Ms. Esther Namboka
- iii. Africa Albino Foundation Uganda. Board member Mr Josseous Nayebare
- iv. Luweero Albino Association Chairperson Mr Richard Seddinda
- v. Mukisa Foundation Executive Director, Dr Florence Namaganda
- vi. Women of Valor Executive Director Ms Remmy Male
- vii. Masaka Albino Association Coordinator Mr Emmanuel Mukasa
- viii. Asante Judith (Bududa) Coordinator Ms Naomi Muganwa

#### **The day in brief**

- Luweero District Albino Association, one of the community based organizations under the Umbrella acted out an educative skit highlighting the plight of children born by a mother with albinism. The ill-treatment husbands and children face associated to albinism is enormous. It is a pitiful situation that even without having the condition yourself, children still face discrimination because of her parents.

- Anthony Balikowa, a young man living with albinism with great talent composed a song and sung it on the day. The message of the song is stop discrimination and embrace albinism as us
- During the function, parents and children received some clothing which were highly appreciated.
- Sun screens were also distributed to those who attended.
- First time attendees were impressed and inspired to see other children, parents and exchanged contacts to build a supportive community among themselves



**Mrs. Sylvia Ntambi Equal Opportunity Commission in brown the front and Mr. Nayebare (with microphone) explaining medical aspect of albinism**





***Hon Minister of State for education and Sports, Hon Charles Bakabulindi addressing the audience***



***A cross section of the people who attended the function***

## D. NEW OFFICE LOCATION

Albinism Umbrella shifted to Plot 189 Namuli road Bukoto in July 2017 leaving a small shared office in Ntinda. This was done to serve our team better in own offices. It however calls for more fundraising to maintain the ever increasing needs of the albinism community Through awareness, we have registered an increase in the number of people seeking our services. From 262 members in 2015 to 375 by close of 2017

Current contact information.

Plot 189 Nmauli Road Bukoto

P.O. Box 3262 Kampala

Website: [www.albinismumbrella.com](http://www.albinismumbrella.com)

Email: [info@albinismumbrella.com](mailto:info@albinismumbrella.com)

Facebook: [facebook.com/albinismumbrella](https://facebook.com/albinismumbrella)

Twitter handle: [@albinismumbrell](https://twitter.com/@albinismumbrell)

## E. INTERNATIONAL LINKS

1. Albinism Umbrella in its efforts to raise awareness embraces many students from overseas. It has continued to do this and helped two students in 2017 work on their project. **Ms. Tyler Schank from Nebraska University, USA** a photo journalist worked with the Umbrella team for two weeks to complete her research project. Visit <https://www.tylerschank.com>.
2. Ms Amy Fallion form Australia published, a story in the crinkling news, an Australian newspaper about albinism in Uganda. The article featured a Ugandan couple who have four children, three of whom are living with albinism. They have so far cooped well with the challenges and are together raising their children. They notably cry of the high cost of their daily protection gears which are expensive yet they are a must have to maintain a good and health skin. They expressed gratitude to Albinism Umbrella that has continued to provide these cremes free of charge whenever available.
3. **Albinism doll.**

September is an albinism awareness month in South Africa On 13<sup>th</sup> September 2017, the world beheld the first ever albinism doll named Alexa Mala Byran Introduced the doll to show kids that everyone is beautiful. It aims to empower kids with albinism to easily identify with it and hence reduce stigma and discrimination Alexa. Byrans newest doll rocks a blonde TWA ( teeny weeny afro) true to the hair color of people with albinism.

# At last, a doll just like me

Whenever **Liz Ayebare**, a nine-year-old Ugandan girl, sees dolls, they never look like her.

BY Amy Fallon

**LIZ** was born with albinism, a genetic condition which means she lacks melanin, a chemical in our bodies that gives our skin, eyes and hair a certain colour. Liz, like many other albino people, has pale skin, greyish eyes and blonde hair.

The condition affects about one in 17,000 people around the world, but in some countries in Africa, including Uganda, one in 5,000 are albino, according to the Ugandan charity Albinism Umbrella.



**ALBINOS ATTACKED**

The condition can put people at great risk of sunburn and may affect their vision. But some albino people are also treated very differently from non-albinos and even attacked in countries like Tanzania, a neighbour of Uganda.

"Life's hard for them," says Liz's mother Scovia Nsimenita, who has two other albino children aged four and 10 months, and another aged six who is not an albino.

"They are discriminated in schools, in the community." As a result, many parents stop their albino children from going out in public.

**THE FRIZZY EFFECT**

But now one woman in South Africa is trying to make others understand that albinos are just like everyone else - through dolls.

Dollmaker Mala Bryan has created an albino doll called Alexa, who, with her blonde frizzy hair, looks a bit like Liz.

Ms Bryan says it is

important that dolls represent everyone.

"Hopefully, this will help children play and learn to love and understand people of all races," she says.

**BACK TO NORMAL**

Alexa took two years to design and Ms Bryan says the feedback so far has been "absolutely amazing". "Children and adults are loving the dolls," she says.

Liz also approves of Alexa. "I would like to play with her," she says.

Olive Namutebi, an albino woman who began Albinism Umbrella in 2016, likes the idea of an albino doll.

"Why not? If people see this doll it may mean for some that when they do meet an albino person in real life this will not be a new thing," she says.



Left and top, 'Alexa' is a new albino doll, created by doll maker Mala Bryan in South Africa, to represent people with albinism. PHOTO Mala Bryan/Malleville Toys Above, Scovia Nsimenita holds one of her albino children, 10-month-old Solomon, with her other children, from left, Tiffany, 6, Melira, 4, and Liz, 9, at their home in Kampala, Uganda. PHOTO Amy Fallon

## 4. The 7th Uganda UK convention



Olive Namutebi addressing guests at the convention.



In fulfillment of the Speakers pledge to voice our plight to the diaspora, Olive Namutebi was privileged to attend the 7<sup>th</sup> UK convention in London. She was further given a golden opportunity to address the high delegation audience and call for support for the various issues affecting the albinism community.

### **Major highlights of the convention outcome.**

1. Mr. Willy Mutenza, a very instrumental Ugandan, the chairman of the convention pledged to educate one child with albinism for one year. He also financed my travel ticket to the convention in conjunction with the Parliament of Uganda.
2. Ms. Teddy Curmon, a proudly proclaimed Karamojong contributed to Cathy Ngambe school dues of Shs 600,000/= which was needed to finish her nursery teaching course at Mother's Union Education centre Mukono. Cathy is now doing her final term in computing to formally qualify as a nursery teacher. Cathy 17 years is among the many who are abandoned by her parents and left with her old auntie who could not support the secondary education and opted to a short course of nursery teaching. This however also had proved hard as the arrears were for two terms. Thanks to the diaspora family. Please continue supporting us.
3. Through the contacts got at the convention, I was able to easily approach the Central Broadcasting Service (CBS radios) for sponsorship of an awareness campaign about albinism. CBS radio has given us a slot to carry out awareness about the condition for three months starting January 2018.
4. There was great awareness created among the attendees who flocked my stall in appreciation for the enlightenment about the condition.





*The Vice president Hon Edward Sekandi and the Speaker of Parliament visiting Olives stall at the convention*

### **Other activities.**

- Equal opportunity commission- yet to sign MOU to be fully engaged in its activities and help our distressed mothers whenever legal action is needed.
- Dr Hon Betty Udongo of Pincer Training and Research Institute in collaboration with Albinism Umbrella have come up with a prototype sunscreen. It is organic and we look forward to have it undergo the standard tests. The preliminary results are awesome on the skins of PWA.
- International Awareness Day will be held in Eastern Uganda, one of the major hubs of person with albinism.
- Ministry of Education: Ministry contacted to have sensitization in schools, provide extra time for PLE candidates living with albinism.
- Ministry of Gender, Labor and social development. A meeting held with Commissioner of Equity and Rights in September aimed at creating awareness of the plight of the albinism community and seek for support thereof.

### **Call to action**

2018 Albinism Umbrella is to focus on local production of sunscreens. The concept has been proved right. It further needs a rigorous scientific process to have certification. Partner with us in any of the following ways

- Provide financial support to carry out tests for the standard and quality mark from Uganda National Bureau of Standards UNBS and National Drug Authority at a cost Ushs 10m. (ten million shillings only)
- Recommend credible scientists to test the sun protection factor (SPF) of each oil used in the lotion and other technical support.
- \$100 can currently make 30 bottles of 250g each for the desperate ones who will not wait for certification.
- Come on board for the albinism school awareness program by printing materials, provision of transport for the team and supporting the radio talk shows.