



ALBINISM UMBRELLA

2019 Annual Report

Building a society in which People with Albinism are dignified



Contents

Building a society in which People with Albinism are dignified	ii
Introduction.....	4
Vision.....	4
Mission.....	4
Strategic Goal.....	4
Objectives	4
Programs and activities.....	4
Who we work with.....	4
A Review of 2019	5
Summary of Achievements against Organisation objectives/ Areas of focus	5
Activities implemented in 2019 as per the strategic areas of focus	7
1.0. Strategic area 1:	
To put persons with albinism’s rights and well-being at the heart of policy makers.....	7
a) 2019 Fundraising Walk with the Parliament of Uganda	7
b) Launch of the Spatial Mapping Report for persons with albinism in Eastern Uganda	8
c) Participation in the International Albinism Awareness Day	12
d) Press Conference at Ministry of Health Headquarters on 10th June 2019.....	13
Launch of the Situational Analysis Report on Albinism in Uganda on 13th June 2019	14
Strategic Area 2: To give a voice to persons with albinism.....	15
a) The Ambassador Women’s Rights and Gender Equality visits Albinism Umbrella.....	15
b) A Car washing drive to keep Children with Albinism in school	20
c) Commemorating the 16 Days of Activism Against Gender Based Violence.....	22
Strategic Area 4: To develop the local persons with albinism network in order to deliver a powerful force for change.....	24
a) Provision of sun screens and Binoculars to persons with albinism	24
b) Development of Albinism Umbrella strategic plan 2019-2023	25
6.0. Key notes to take	25
7.0. Albinism Umbrella Team	26
Financial Statements.....	27



Message from the Chairperson interim Board

Dear Friends,

On behalf of the Interim Board of Directors, it is with great pleasure to present to you the Albinism Umbrella Annual Report 2019.

As I reflect on the first year of our tenure as an Interim Board, we are pleased with the strides the Umbrella continues to take to ensure that the lives of the Persons with Albinism (PWA) are protected, their livelihood supported and dignity promoted.

In this report, we celebrate yet another successful year of developing and up scaling working approaches that enhance our work. Among the outstanding achievements registered, is the successful development of the ever first strategic plan that has enabled the Umbrella to offer services in a strategic manner to shape the future it desires. The Strategic plan will enable us to consolidate our work, develop holistically and coordinate all the functions. It also seeks to increase Albinism Umbrella's relevance to her members in a clearer and coherence manner.

Further, Albinism Umbrella was able to undertake spatial mapping research to profile persons with albinism in Eastern Uganda (10 districts include Budaka, Bududa, Butaleja, Buyende, Manafwa, Mayuge, Kamuli, Kumi, Sironko and Soroti). During the launch of the findings we strategically engaged

different policy makers to support efforts towards empowerment, inclusion and socio-economic advancement of PWA.

Our gratitude goes to our members and regional structures and communities that have received our support and utilized it in the right way. We also wish to appreciate all those who made invaluable contributions that made it possible to achieve these strides. Firstly, to our development partners, who have continued supporting our programmes that reach out to PWAs all over the country.

Secondly, to my fellow board members and Staff at Albinism Umbrella under the leadership of the Executive Director, who have made us proud by the hard work, commitment and upholding the values and mission of Albinism Umbrella in the various responsibilities you undertake.

Together we contribute to a society in which people with albinism are dignified and realize their full potential.

Enjoy the report.

Mukiibi Proscovia Kibuuka
Chairperson - **Interim Board**

Message from the Executive Director

Dear Partners,

I take this opportunity to first of all acknowledge and thank the Almighty God for His hand in the work that we did in 2019. As our strategic goal states **“To be the partner of choice for persons with albinism in Uganda, ensuring that their lives are protected, their livelihood supported and their dignity promoted”**, 2019 was a good rehearsal to its attainment. I appreciate the Albinism Umbrella Interim Board of Directors, staff and partners for the work well done in amplifying our voice.

2019 saw Albinism Umbrella get its first Strategic Plan 2019-2023 which constricted our work to four areas of health, social justice, livelihood and security as per the voices of Person with albinism. Stigma and discrimination still top the list of challenges faced by persons with albinism and thus advocacy and lobbying are an interwoven aspect of our work. Through this we were able to increase our partners in 2019 like Oxfam Uganda, DRF, GIZ, UN Human Rights, Equal opportunities Commission and Barefoot law.

The major accomplishments include; the annual fundraising walk for an albinism center organized by The Parliament of Uganda in January, the launch of the spatial mapping report in May while the year’s IAAD (International Albinism Awareness Day) was



Olive Namutebi
Executive Director -
Albinism Umbrella

the first joint celebration made with other albinism organizations. There were many activities to mark the day and this was possible with support from UN Human Rights.

A situation analysis report dubbed **“Enhancing Equality and Countering discrimination against Persons with Albinism”** was also launched in collaboration with the Equal Opportunities Commission. The year was crowned with a high-powered delegation of The Dutch ambassador for women’s rights and gender equality of the Ministry of Foreign Affairs of the Netherland in October. Ms. Mette Gonggrijp appreciated the boldness of women with albinism displayed in sharing their daunting stories of discrimination and resilience.

We envisage a more rigorous 2020 geared at cementing the work done so far particularly to complete spatial mapping of PWA for the rest of the country and to build regional and sub region structures for the growth of Albinism Umbrella growth and to unify the albinism fraternity.

Olive Namutebi

Introduction

Who we are	Albinism Umbrella is a voluntary, NGO that consists of people with albinism, human rights sympathizers, and all other albinism well-wishers. Albinism Umbrella was established in 2015 and fully certified in 2017. It was set up with the ultimate aim of having a joint voice in Uganda.
Vision	A society in which people with albinism are dignified and realize their full potential.
Mission	To promote and protect the rights of persons with albinism in Uganda through research, partnerships and advocacy for their improved wellbeing.
Strategic Goal	To be the partner of choice for persons with albinism in Uganda, ensuring that their lives are protected, their livelihood supported and their dignity promoted.
Objectives	<ol style="list-style-type: none"> 1. To put persons with albinism’s rights and well-being at the heart of policy makers. 2. To give a voice to persons with albinism. 3. To build a community of professionals that put issues of albinism within their work. 4. To develop the local persons with albinism network in order to deliver a powerful force for change 5. To build and strengthen albinism Umbrella for institutional sustainability
Our Niche	<ul style="list-style-type: none"> • Health • Security • Livelihood • Social justice
Our Values	TRIPE - Team work Respect for the right of others Integrity Professionalism Excellence
Who we work with	<ol style="list-style-type: none"> 1. Community Based Organizations <ul style="list-style-type: none"> • Luwero District Albinos’ Association • Lira Albinism Association • Dorcas Tabitha charity - Kayunga • Masaka Association of Persons with Disabilities living with HIV&AIDS (MADIPHA) • Masaka Albino Association • Albino Organization for Bundibugyo and Ntoroko Districts. • Asante Judith Albinism Support Organisation Uganda - Bududa • Women and Children with albinism • Source of the Nile Union of Persons with Albinism (SNUPA) 2. Current Donors <ul style="list-style-type: none"> • Disability Rights Fund - DRF • GIZ • VOICE - OXFAM Novib 3. Government institutions <ul style="list-style-type: none"> • The Equal Opportunities Commission • The Parliament of Uganda 4. Health Institutions <ul style="list-style-type: none"> • Uganda National Association of Community and Occupational Health-UNACOH • Mengo Hospital 5. Legal and Human Rights Activists Organizations <ul style="list-style-type: none"> • BareFoot Law - BFL • Uganda Women’s Network - UWONET • Office of the High Commission for Human rights (OHCHR) • Kampala Young Women Alliance on the Elimination of Violence against Girls and Women

A Review of 2019

To Albinism Umbrella, 2019 was a positive year given the tangible results registered and important lessons learned that opened up a number of opportunities. In reference to 2019 work plan, over 70% of the activities were implemented and achievements registered as indicated in this report. We have seen tremendous growth in areas of partnerships formation, organizational capacity, membership and influence to human rights and policy actors.

Summary of Achievements against Organisation objectives/Areas of focus

Objective/Area of focus	Achievements
<p>1 To put persons with albinism's rights and well-being at the heart of policy makers.</p> 	<p>Albinism Umbrella spearheaded a fundraising strategy with an aim of constructing a rehabilitation center for persons with albinism. The event is held annually at the beginning of the Parliament week. This activity has been an eye opener to many policy makers towards the needs and issues affecting persons with albinism.</p>
	<p>During the launch of the Spatial mapping report, Albinism Umbrella strategically engaged different policy makers with the aim of laying strategies to support efforts towards empowerment, inclusion and improvement in socio-economic activities of persons with albinism in Uganda.</p>
	<p>Albinism Umbrella promoted inclusion by engaging persons with albinism in different activities during the IAAD week. Recommendations were given to stakeholders like Equal opportunities Commission, Ministry of Health for action</p>
<p>2 To give a voice to persons with albinism.</p> 	<p>Albinism Umbrella held a fundraising campaign to raise funds for scholastic materials for children with albinism. The objective was to enroll more and keep these children in school to attain an education.</p>
	<p>As one of the Voice project grantees, we delightfully hosted the Ambassador Women's Rights and Gender Equality Ms. Mette Gonggrijp from Netherlands to witness the plight of persons with albinism and share their stories.</p>
	<p>Albinism Umbrella participated in the consultative meeting on the draft bill for persons with albinism. This is still under formulation</p>
	<p>Albinism Umbrella in conjunction with Spotlight Initiative provided a platform to persons with albinism to participate in commemorating the 16 Days of Activism against Gender Based Violence</p>
	<p>Persons with albinism actively amplified their voices while performing different activities during IAAD week including; press conference, sports, flyer distribution and report launch.</p>

3

To build a community of professionals that put issues of albinism within their work.



On behalf of persons with albinism, Albinism Umbrella received 500 pairs of binoculars from the Rotary Club of Nkumba. This donation was given towards the enhancement of vision for PWA who may not have access to eye contact lenses. Albinism Umbrella received funds to a tune of four million shillings from Pride microfinance and Finance Trust bank to buy sunscreens.

4

To develop the local persons with albinism network in order to deliver a powerful force for change.



Albinism Umbrella took part in the Annual Voice Indaba (Conference) in Nairobi Kenya. Stories that were shared about albinism inspired many lives. From this engagement ALBINISM UMBRELLA was recognized at regional level.

Carried out human rights awareness/training in the parishes of Kikyusa, Nakaseke, Katikamu, Nakasongola Luweero trading centre in Luweero district with co-facilitation by Barefoot law. 34 persons learnt about the basic legal information.

5

To build and strengthen albinism Umbrella for institutional sustainability.



Increased partnerships and membership building with other organizations such as DRF, GIZ, Bare Foot Law, UWONET, Women Alliance against Violence, Mengo hospital, among others

Albinism Umbrella successfully developed a 5-year strategic plan (2019-2023) in order to shape the future that we aspire to have.

Albinism Umbrella received two organizational capacity building grants from DRF and GIZ. Among the objectives are to develop a constitution, forming up regional structures, policy formulation, securing an accounting software among others.

Continued documentation and ALBINISM UMBRELLA visibility through communications platforms such as website, social media platforms.

Activities implemented in 2019 as per the strategic areas of focus

Strategic area 1: To put persons with albinism's rights and well-being at the heart of policy makers.

a) 2019 Fundraising Walk with the Parliament of Uganda

In 2016, the Parliament of Uganda initiated the Annual Parliament Week program to give the general public an opportunity to meet and engage with their Members of Parliament and participate in a plenary sitting to discuss issues of concern.

The program is kicked off by a fundraising walk towards the construction of a Rehabilitation Centre for Persons with Albinism in Uganda. This dream which was initiated by Olive Namutebi, the Executive Director of Albinism Umbrella requires shillings 105 billion to become a reality.



Deputy Speaker of Parliament Hon Jacob Oulanyah flagging off the Parliament week with a fundraising walk on January 13, 2019.

The event was headed by the Parliamentary Commissioner Cecilia Ogwal on behalf of the Speaker of Parliament, other Members of Parliament, representatives from various ministries, departments and agencies, private organizations, Non-Governmental Organizations as well as religious leaders were also in attendance.

Points to note from the day.

Hon Cecilia Ogwal said that people with albinism need to be given hope and courage from within the families and communities they live, for their lives are full of agony. "Silent discrimination is worse than open discrimination, your lives are in danger all the time." She added.

This year's contributions which saw Uganda Shillings 46 million being raised came from various institutions including; departments of Parliament, Members of Parliament, Government Ministries, Development partners and individuals



New Vision representative (first from left) handing over a cheque worth shs10 million towards the construction of an albinism centre

b) Launch of the Spatial Mapping Report for persons with albinism in Eastern Uganda.



Launch of the of the spatial mapping report on 21st May 2019 at Hotel Africana- Kampala

Albinism Umbrella in partnership with Voice, through Oxfam Uganda and other stakeholders convened for a dissemination of research findings on spatial mapping and profiling of persons with albinism (PWA) in Eastern Uganda. Key to the launch was laying strategy for supporting efforts towards empowerment, inclusion as well as improvement in socio-economic activities of persons with albinism in Uganda. The 10 districts include Budaka, Bududa, Butaleja, Buyende, Manafwa, Mayuge, Kamuli, Kumi, Sironko and Soroti.

While giving her remarks, Olive Namutebi the Executive Director of Albinism Umbrella used her gave her experience as a motivation to the work of Albinism Umbrella.

"I faced rejection from my father while growing up just like most children with albinism however, my mother never gave up on me as she worked tirelessly to give me an education. I realized the need to help fellow persons with albinism facing stigma and discrimination thus forming up Albinism Umbrella." Olive narrated.



Olive Namutebi giving her welcoming remarks.



In the picture above, Inez Hackenberg, the Global Linking and Learning Coordinator for the Voice Project observed that the Voice Project is concerned about amplifying the voices of groups of people that face any form of discrimination and marginalisation, and this includes persons with albinism. The program supports groups of Albinism Movement in Kenya, Mali, Tanzania, and Uganda among other countries. *'The digital method of collecting data is such a unique innovation that Albinism Umbrella needs to share with other Voice grantees, I pledge to support Albinism Umbrella in its future aspirations.'* She said.

Presentation of research findings.



Dr. Arthur Bagonza giving a presentation of the findings in the spatial mapping report.

“The population of persons with albinism in Uganda is based on speculations due to absence of concrete statistics, this calls for a National spatial mapping to add on the 10 concluded districts, the report provides evidence based data about people with albinism, the challenges faced, opportunities, general situation in terms of health, education, security, self and society perceptions, done using Global Positioning System and Open Data Kit.” Dr. Arthur Bagonza clarified.

Summary of the findings:

- Sironko (20.2%), Bududa (17.9%), Manafwa (17.5%) have the highest populations of PWA followed by Kamuli and Buyende (10.3%).
- The numbers of children below 18 years with albinism were highest in Sironko (26.4%) and Bududa (25.6%) districts
- The highest number of adults was found in Buyende (16.9%) and Kamuli (13.8%) districts respectively.
- 67.7% of persons with albinism did not know the causes of albinism.
- 76% did not know what causes skin cancer and how to prevent it.
- 75.7% of the respondents have an eye problem. Only 20.5% have ever had an eye check-up at a cost that ranges between 30,000/= to 900,000/= with the average being 173,021/=.
- 72.2% of persons with albinism could not read clearly because they did not have any reading glasses, however almost half of the respondents 47.5% admitted to not using anything.
- Also, 43.5% of the children reported cases of discrimination by fellow pupils, at home and within the community. having been discriminated becAlbinism Umbrellase of albinism.



Anatoli Mulekerwa from Police calling for close collaboration with Police

In the picture, Afande Anatoli Mulekerwa-Deputy Commissioner Department of Community Policing in the Uganda Police requested that PWA actively cooperate in their communities for effective community policing and pledged to partner with Albinism Umbrella to ensure safety of PWA. He further suggested that a forum be organized to sensitize police officers on issues concerning albinism.

Remarks by the chief guest



Mr. Bernard Mujuni who represented the Minister of Gender, Labour and Social Development commended the Executive Director of Albinism Umbrella for her impressive networking and lobbying abilities. He advised Albinism Umbrella to consider benefiting from a range of development programs that the government has rolled out to steer Ugandans to self-sustenance such as Youth Livelihood

Program, USE, UPE, Students Loan Boards. Albinism Umbrella should seek affirmative action as the next step to get active inclusion and action for PWAs. He further asserted that

Bernard Mujuni, delivering remarks on behalf of the Minister of Gender

“...the law isn’t a solution to everything; the true change and the biggest solutions lie within us as we intervene in our homes and communities towards PWA...”

His recommendation was that all government sectors such as Ministry of Health, Ministry of Education, Ministry of Gender, Labor and Social Development should be presented with the report for an inclusive decision-making process. He finally congratulated Albinism Umbrella on the ground breaking research and invited the team to launch research report.

Recommendation from the report

- Government should make sunscreen an essential drug easily available in hospitals all over the country.
- Albinism Umbrella should continue creating awareness about albinism, myths and challenges.
- Develop a tracking profile of persons with albinism using a GPS profile tracker for security and service delivery.
- Skills training in small scale income generating activities so that PWAs can be employed in the confines of their homes for protection from sunrays.
- Capacity building to enhance professional running of Albinism Umbrella.
- Lobbying for employment of professional PWAs in key government ministries and bodies as well as Civil Society Organizations

Future Prospects

To undertake a similar research in other parts of the country (west, north and central) so as to have an evidence based representation of the whole country and have a clear nationwide perspective of persons with albinism.

c) Participation in the International Albinism Awareness Day

JUNE 13th 2019
INTERNATIONAL
ALBINISM
AWARENESS DAY
Still Standing Strong



Albinism Umbrella



Games, Sports, Report launch and much more
A day full of fun activities Awareness, Recognition & Joy



The UN Human Rights (OHCHR) supported the albinism fraternity to have the first ever joint celebration of International Albinism Awareness Day (IAAD). The theme for 2019 was “*Still Standing Strong*” which saw different organizations and associations of persons with albinism come together in preparation for this special day. Albinism Umbrella, Uganda Albinos Association (UAA), Women and Children with albinism, Source of the Nile Union of Persons with Albinism (SNUPA) participated in these events. Equal Opportunities Commission (EOC) was also represented during the week-long activities which started with a press conference, flier distribution, skin cancer screening, sports and launch of the situation analysis report.

Key Highlights of the week-long commemorative activities

I) Press Conference at Ministry of Health Headquarters on 10th June 2019

A press conference was held at the **Ministry of Health** Headquarters where an albinism awareness week was officially launched in the presence of Albinism Umbrella, People with Albinism and the media. Key speakers were representatives from the Ministry of Health, the Executive Director of the Cancer Institute, representatives from Equal Opportunities Commission and UN Human Rights. The event served to raise awareness of the health challenges faced by persons with albinism and to call for action from the responsible actors.

II) Raising community awareness about albinism on 11th June 2019



Persons with Albinism distributing fliers with key messages on albinism

III) Provision of healthcare services to persons with Albinism on 12th June 2019

During the commemorations, healthcare services were also extended to persons with albinism led by the ministry of Health.



Dr. Harry Mpewo doing cancer screening, one of the services provided by Lions Club in celebrating IAAD.

IV) A Sports event for Persons with Albinism

During the commemorations, a sports event was organized to create public awareness and visibility for albinism.



Team members celebrating a goal at Lugogo show ground organized to promote equality and non-discrimination. This was done alongside an exhibition and blood donation on 12th June.

V) Launch of the Situational Analysis Report on Albinism in Uganda on 13th June 2019

The IAAD is also a platform to advocate for the promotion and protection of human rights of PWA in Uganda. On the 13th June 2019, as part of the week-long commemorations, His Excellence Andreas Von Beckreath, the Swedish Ambassador who was the chief guest launched the Situation analysis report entitled; **“Enhancing Equality and Countering Discrimination against people with Albinism in Uganda”**. The purpose of the study was to provide baseline information for interventions towards persons with albinism in Uganda.

In his remarks, the ambassador, emphasized that provision of sunscreens and other protective gears to persons with albinism should be one of government’s priority areas and that albinism awareness is intended to overcome stigma and discrimination among the albinism community. The event was graced by several human rights actors and stakeholders including; CSOs, NGOs, PWA, Government ministries, MDAs, diplomatic community, the UN family, media, the Parliament of Uganda, Equal Opportunities Commission and UN Human Rights.



Launch of the situational analysis report at Grand Imperial Hotel

Key Study Highlights

- It revealed
- Challenges affecting the albinism community in Uganda
- It called for
- Establishing the numbers of persons with Albinism in Uganda
- Mapping existing service providers for PWA and the nature of services they render
- Assessing the level of awareness about the rights of the albinism community among stakeholders and policy makers
- Identifying gaps and giving concrete recommendations to improve the lives of PWA

Strategic Area 2: To give a voice to persons with albinism.

a) The Ambassador Women's Rights and Gender Equality visits Albinism Umbrella.

On October 16, 2019, Albinism Umbrella hosted Ms. Mette Gonggrijp, the Ambassador Women's Rights and Gender Equality from Netherlands. The purpose of the meeting was to get firsthand information from the beneficiaries of the Voice seed grant project how it had changed their lives by sharing stories and experiences about albinism

In attendance were, a delegate from the Netherlands embassy and Oxfam Uganda team, four staff from Oxfam Uganda that is the project assistant, interim Project Coordinator for Voice in Uganda, Governance and Accountability Manager, Head of Programs, parents to children with albinism, adults with albinism, media and Albinism Umbrella staff.



Participants posing for a photo with Ms. Mette

Remarks from Oxfam Uganda Head of Programs

The Head of Programs Oxfam Uganda, Ms. Jane Achen was grateful to have the ambassador get first-hand information from the grantees. She gave a brief about Voice as an innovative grant facility that supports the most marginalized and discriminated people. ***“It aims to amplify and connect the unheard voices in efforts to leave no one behind, Voice is an initiative of and financed by the Ministry of Foreign Affairs of the Netherlands Government as part of their overall policy framework ‘Dialogue and Dissent’ and is executed by a consortium between Oxfam Novib and Hivos”*** Ms. Jane said.

She observed that Voice offered a seed grant to Albinism Umbrella to carry out spatial mapping of persons with albinism in 10 districts in the Eastern part of Uganda. Ms. Achen was also troubled about how persons with albinism face a lot of challenges that include discrimination, stigma, poverty, skin cancer, myths, sacrifices, however, women with albinism face a double discrimination as they are considered a weaker sex with disability. She re-echoed the inspiring stories shared by Albinism Umbrella during the Indaba Voice Conference in Kenya where Phillip Makasi and Olive Namutebi participated and encouraged others to freely share their experiences.



Mette Gonggrijp, the Ambassador Women's Rights and Gender Equality from Netherlands (third from left) giving her remarks.

In her remarks, Ms. Mette appreciated beneficiaries for sharing their personal experiences which were so touching.

“It was time well spent hearing firsthand information from the beneficiaries of the project, I wouldn’t get this by simply reading reports at my desk” she emphasized.

From all the stories shared, she pointed out discrimination and security as the most challenges faced by persons with albinism and added that they are the true ambassadors who can change the

status quo through shaping their lives and exhibiting high levels of confidence both at individual and organizational level.

“I am glad you are preparing way for the next generation to overcome stigma, I can see there is a way for a better future.” she asserted.

Mette concluded that she was happy with Albinism Umbrella’s work in empowering persons with albinism amidst the many challenges that they experience.



In her remarks, the Executive Director Albinism Umbrella felt honored to host the meeting. She appreciated persons with albinism for being open and share their stories which showed self-confidence and acceptance.

“The common community challenge persons with albinism face is stigma and discrimination which can only be addressed by gaining self-acceptance and confidence to change the myths associated with albinism.” Olive asserted.

Sharing personal stories by Persons with Albinism



Joan, Phiona and Kennedy, shared their stories depicting the challenges they encounter and how they are coping.

Discrimination and self-confidence by Brenda.

Brenda is a third year University student pursuing a Bachelor's degree in Business Administration at Makerere University Business School. She was raised by a single mother after her father ran away at her birth claiming that he cannot be a father to a child of her kind.

"I faced a lot of discrimination in my first year at the University, students did not want to share a room with me, nor eat with me, I resolved to do something about it". Through encouragement and mentoring from Albinism Umbrella, I dared to seek a leadership role at the university council, I was unopposed for the Disability Ministerial post a position I hold up to now!" Brenda narrated.

This position has opened doors for her and more other students with disabilities.

"I now have a voice! People listen to me and many offices give me the attention I need"., Brenda proudly added.

Parenting a child with albinism by Leila Nabunya

“At the birth of my girl with albinism, women in the hospital ward uttered a lot of negative words about the uniqueness of my baby that I got terrified about whether my husband would turn up or even pay the hospital bills” Leila said.

Leila is a mother to Pearl Nakacwa, an eight-year-old child with albinism in a family of three children. Unlike for some children with albinism, Pearl is loved by both parents who see her as an equal child like any other. ***“Pearl is a bright girl and I am so proud of her.”*** Leila gratefully asserted.

She added that she had no idea about sunscreens until she connected with Albinism Umbrella which provided her lotions as a remedy for skin damages and appreciated it for this priceless commodity in Pearl’s life. ***“One day children bullied her and reported to the school administration where they were punished. This was a strong warning and gave her more confidence to stand for her rights.”*** Said Leila.

Diana, a single mother

Diana is a single mother with albinism and has two children. She was unfortunate that both her parents abandoned her at birth referring to her as a curse. She was raised by her paternal grandmother up to the age of seven when her father picked her with the advice from the native doctors that persons with albinism are a blessing and source of wealth.

For a period of seven years, Diana was used as an object to attract people to bring money in a shrine. She was made to sit in a strategic place with a basket for collecting money from those who sought counsel from the witchdoctors. ***“I was made to perform various rituals at such a young age some of which I can’t even narrate. During all this time, I was over protected and confined in a shrine without letting me play with other children.”*** Diana recalls her ordeal.

One day, Diana successfully escaped from the shrine and went back to her grandmother’s place with the help of well-wishers. Life was not easy, I needed to make some money for basic needs as grandmother wouldn’t provide much. I became a nanny in certain homes. Unfortunately, even there, discrimination and stigma kicked me out. I was never paid for the work done, I tried restAlbinism Umbrellarants but I was forced to leave as it was claimed that I chased their customers.

“Relationships were not an easy attempt”, Diana narrates. ***“The first man denied any responsibility to our child and abandoned me. I am a mother of twins, who I dearly love & cherish but their father is under constant threats for marrying a ghost.”***



Nakibuuka Diana (third from right) sharing her experience as a person with albinism, a mother of two, a survivor of ritual sacrifice and a victim of domestic violence

b) A Car washing drive to keep Children with Albinism in school.

Findings from the Albinism Spatial Mapping study indicate that many parents are poor that they cannot give an education to their children.

“I am willing to enroll my child with albinism in Universal Primary Education (UPE) program but I cannot afford to provide her with scholastic materials.” A parent in Sironko said.

High poverty rates among families of persons with albinism makes it difficult for parents and care givers to afford scholastic materials, school fees and visual aids. This has increased illiteracy levels among people with albinism.

Albinism Umbrella organized a fundraising car wash to keep these children in school, increase awareness in schools and communities about albinism and provide assistive devices to persons with albinism for a better vision.

The fundraising drive was geared towards;

- Raising funds for scholastic materials for example books, pens, pencils, sets, uniforms, umbrellas and rain coats, wide brimmed hats, shoes among others.
- Creating awareness among stake holders, parents, care takers and teachers of schools where children with albinism attend
- Seeking donations like cloths, toys, sugar, soap, shoes

The envisaged change was;

- Increased enrollment of children with albinism in schools
- Reduced dropout rates in schools
- Increased number of educated PWA
- Increased awareness in schools and communities about albinism
- Self-esteem and confidence built amongst people with albinism



Persons with Albinism participating in the washing of cars.



Persons with albinism inviting people to wash their cars in support of the fundraising campaign.



Albinism Umbrella staff receiving contribution from one of the well-wishers towards the keep the children with albinism in school campaign.

c) Commemorating the 16 Days of Activism Against Gender Based Violence.

On 6th December, a coalition of four organizations including Albinism Umbrella, UWONET, Gals Forum, International and Young Women Alliance for Human Rights joined the rest of the world to commemorate the 16 Days of Activism against Gender- Based Violence which is an annual international campaign that kicks off on 25 November during the International Day for the Elimination of Violence against Women, and runs until 10 December on Human Rights Day.



Programs Officer UWONET with Ayebare Elizabeth, a girl with albinism passing out a message to eliminate violence against women and girls with albinism.

16 Days of Activism is used by individuals and organizations around the world to call for the prevention and elimination of violence against women and girls. Worldwide, most women are subjected to violence in various forms and this is largely attributed to their gender. However, women with disabilities, those with albinism to be precise face a double harsh treatment due to their gender and disability.

Jean, the Executive Director of Young Women Alliance for Human Rights took a session on Violence which she explained as an act that causes emotional/ physical torture on a person. Forms include like economic, sexual, physical, emotional and gender based violence. She opened a platform for the participants to share their stories in line with gender based violence.

Sharing our Stories



Emotional violence at school.

“Life in boarding section was a nightmare for me, being the only student with albinism at school, I faced all kinds of discrimination and stigma caused by the myths associated with albinism. I recall the worst experience I encountered when I was left alone in the dormitory by fellow students. They run away claiming that I was going to disappear at a certain point. I felt traumatized to the extent that I lost respect for teachers who I expected to come out and condemn the act but rather went silent”. Allen narrated.

Allen now works with the Parliament of Uganda as a Technical Assistant M&E under Corporate Planning and Strategy department. *“The parliament offered a good working environment with appropriate devices that help me deliver my work effectively”.* Boasts Allen.



Scovia a mother of three children with albinism and Allen Bonabana sharing their stories during the 16 DOA

Scovia is a mother of four with three children with albinism. *“Contrary to other fathers who deny their children with albinism, my husband looks at our children as a blessing and a gift from God”* Scovia reported.

She said she had never faced challenges with being a parent to children with albinism until when her first born daughter was denied a place in boarding section.

Elizabeth Ayebare had attended the said school since kindergarten up to primary five without any health complication or form of indiscipline. In primary five, all pupils in her class were required to join boarding section in preparation for final primary leaving examination’s hectic reading schedules. It is at this point that Elizabeth faced one of the worst injustices

on grounds of her skin color as the headmaster of the school made it clear that their school had no special accommodation for a pupil with albinism. This did not only cause mental torture to her parents but also caused emotional violence to Elizabeth. Fortunately, Albinism Umbrella intervened and presented the case to the Equal Opportunities Commission where the school faced the law on grounds of human rights violation and discrimination cases.

“That aside, I have never faced any harsh treatment from my husband, family or society” Scovia added.

Yvonne the Programs Officer UWONET said that stories shared by women with albinism are so unique from what is shared by their counterparts and are a great insight to the gender activists. She pledged to always engage Albinism Umbrella and women with albinism at large in UWONET activities/programs as a way of raising their voices against the rampant violence exercised among them.

Strategic Area 4: To develop the local persons with albinism network in order to deliver a powerful force for change.

a) Provision of sun screens and Binoculars to persons with albinism



Executive Director holding samples of sunscreen lotions in the picture above

It should be noted that the cost of a bottle of sunscreen lotion is very high and rare on Ugandan market. This exposes persons with albinism to harmful effects of direct sun rays like damage of the

skin and skin cancer. Albinism Umbrella with support from African Albino Foundation Netherlands (AAFU) found it important to provide persons with albinism with sunscreens at no cost. With mass sensitization, a big number has applied the lotions and reduced challenges with the skin.



From Right, Brenda Bonabana, Olive Namutebi and Peace Mataaga receiving pairs of Binoculars from Rotary Club of Nkumba.

The health of Persons with Albinism is compromised by visual challenges and yet many of them cannot afford paying for an eye checkup or even assistive devices due to poverty. Albinism Umbrella was privileged to receive binoculars from the Rotary club of Nkumba in support with Rotary Club of Lancaster USA.

Free eye screening and appropriate contact lenses were given out to selected persons with albinism. In February 2017, 60 received free eye examination and two pairs of lenses each. In June 2019, the same club provided 500 pairs of binoculars for both children and adults. So far, over 300 pairs have been distributed.

In partnership with Care Uganda-a UK based charity, we carried out albinism awareness in the areas of Luweero. A total of 140 village health teams were trained in the sub counties of Nyimbwa, Makulubita, Kiyanda Mawale, Kanyanda and Kangave.

Strategic area 5: To build and strengthen albinism Umbrella for institutional sustainability.

a) Development of Albinism Umbrella strategic plan 2019-2023

Strategy formulation and implementation is one of the important tools that a successful organisation requires. In January 2019, two meetings were conducted to review the organization vision, mission, core values as well discussing the problem analysis.

A five-year strategic goal was set that is *“To be the partner of choice for persons with albinism in Uganda, ensuring that their lives are protected, their livelihood supported and their dignity promoted”*.

In addition, 5 strategic areas of focus were developed to reflect the context within which Albinism Umbrella will be working for the next 5 years which are not limited to, being the preferred voice for all persons with albinism in Uganda, putting the rights of persons with albinism in the minds of policy makers, having a body of professionals who think about persons with albinism, develop the local persons with albinism network in order to deliver a powerful force for change as well as building and strengthening albinism Umbrella for institutional sustainability while pledging commitment to quality and integrity.

6.0. Key notes to take

Persons with albinism need to be empowered with human rights, advocacy and livelihood skills to equally participate in different programs like their counterparts.

Giving persons with albinism a platform to share their stories and experiences boosts their esteem and confidence. We observed this during some of ALBINISM UMBRELLA participatory sessions where we encouraged members to speak out their hearts. With this, persons with albinism share freely and encourage each other based on life experiences.

It is important to create awareness raising to parents, care takers and the communities where children with albinism live. This creates an enabling environment suitable for child development.

Furthermore, involving parents of children with albinism in our programs empowers them to put in to practice what they have learnt. These parents become change agents of the better society for their children.

7.0. Albinism Umbrella Team

Board of Directors

NAME	ROLE
Proscovia Kibuuka Mukiibi	Chairperson
Allen Bonabana	Vice-Chairperson
Pheonamyra Nagujja	Treasurer
Juliana Nantaba	Secretary
Joseous Nayebare	Member
Olive Namutebi	Executive Director

Secretariat

NAME	ROLE
Olive Namutebi	Executive Director
Henry Mujuni	Finance and administration Officer
Phionah Nicole Nantaba	Administration Assistant
Janepher Nanyondo	Programs Assistant

ALBINISM UMBRELLA

Annual Report and Financial Statements
For the Year ended 31st December 2019

STATEMENT OF COMPREHENSIVE INCOME AND EXPENDITURE

	Note	Year ended	Year ended
		31/12/2019	31/12/2018
		Ushs	Ushs
INCOME			
Grant from Oxfam		114,097,710	194,660,779
Balance CF from 2018		40,087,445	
Total		154,185,155	194,660,779
EXPENDITURE			
Staff Costs		42,200,000	37,515,000
Office Running Costs		22,328,151	22,604,479
Program Expenses		34,952,860	88,253,855
Professional & Consultancy Fees		16,070,000	6,200,000
Depreciation		1,211,750	518,750
Total expenditure		116,762,761	155,092,084
Surplus/(Deficit)		37,422,394	39,568,695
Surplus/(Deficit) for the year		37,422,394	39,568,695

Annual Report and Financial Statements
For the Year ended 31st December, 2019

STATEMENT OF FINANCIAL POSITION	Note	Year ended	Year ended
		31/12/2019	31/12/2018
		Ushs	Ushs
Assets			
Property and Equipment		3,082,000	2,193,750
Current Assets			
Receivables & Prepayments		-	2,200,000
Cash and Cash Equivalents		59,921,320	40,101,245
Total Assets		<u>63,003,320</u>	<u>44,494,995</u>
Financed By:			
Contribution from Founders (SOCE)		3,177,300	3,177,300
Retained Reserves (SOCE)		58,326,020	37,617,695
Non-Current Liabilities		-	-
Current Liabilities		1,500,000	3,700,000
Total Funds		<u>63,003,320</u>	<u>44,494,995</u>

The financial statements were approved by the trustees on.....and were signed on its behalf by:



Executive Director



P1	62	38	110
P2	50	51	106
P3	47	53	100
P4	62	60	122
P5	64	59	123
P6	57	50	107
P7			
			270 265 735
			Φ: Good
			1st
			2nd
			3rd



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