



# ANNUAL REPORT 2022

Celebrating Our Gains Together



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## LIST OF ACRONYMS

<b>AAN</b>	African Albinism Network
<b>AGM</b>	Annual General Meeting
<b>BOD</b>	Board of Directors
<b>CAO</b>	Chief Administrative Officer
<b>CBM</b>	Christian Blind Mission
<b>CBOs</b>	Community Based Organizations
<b>CLA</b>	Citizen Led Accountability
<b>CSC</b>	Community Score Card
<b>CSU</b>	Cheshire Services Uganda
<b>CSOs</b>	Civil Society Organizations
<b>CRPD</b>	Convention on the Rights of Persons with Disabilities
<b>DCDO</b>	District Community Development Officer
<b>DRF</b>	Disability Rights Fund
<b>DEO</b>	District Education Officer
<b>DHO</b>	District Health Officer
<b>EOC</b>	Equal Opportunities Commission
<b>EFPA</b>	Elgon Foundation for Persons with Albinism
<b>FGDs</b>	Focus Group Discussions
<b>FIDA-U</b>	Federation of Women Lawyers Uganda
<b>GIZ</b>	Germany Cooperation
<b>IAAD</b>	International Albinism Awareness Day
<b>IDPD</b>	International Day of Persons with Disabilities

<b>IEC</b>	Information Education and Communication materials
<b>LLL</b>	Livening the Linking and Learning
<b>MGLSD</b>	Ministry of Labor Gender and Social Development
<b>MOH</b>	Ministry of Health
<b>MoES</b>	Ministry of Education and Sports
<b>MOU</b>	Memorandum of Understanding
<b>NCPD</b>	National Council for Persons with Disabilities
<b>NMS</b>	National Medical Stores
<b>NAPPWA</b>	National Action Plan for Persons with Albinism
<b>NUDIPU</b>	National Union of Disabled Persons of Uganda
<b>OHCHR</b>	Office of the High Commissioner on Human Rights
<b>PWD</b>	Persons with Disabilities
<b>OPDs</b>	Organizations of Persons with Disabilities
<b>OPM</b>	Office of the Prime Minister
<b>RCC</b>	Residential City Commissioner
<b>SASA</b>	Self-awareness and Self-Acceptance
<b>SDGs</b>	Sustainable Development Goals
<b>SIELEH</b>	Sustainable Inclusive Economic Livelihood and Eye Health
<b>SNUPA</b>	Source of the Nile Union for Persons with Albinism
<b>UAA</b>	Uganda Albino Association
<b>UNHCR</b>	United Nations of High Commissioner for Refugees
<b>WHC</b>	Wakisi Health Center

## EXECUTIVE SUMMARY

During 2022, Albinism Umbrella made great strides in promoting the rights of persons with albinism while working in partnership with government, development partners, civil society.

In a bid to Put persons with albinism's rights at the heart of policy making, the organization launched a spatial mapping report on Persons with albinism in the Western, Northern and Central regions and disseminated research on refugees with albinism in the settlements of Kyaka II, Nakivale and Rwamwanja. In the same vein, the National Action Plan for Persons with Albinism (NAPPWA) was launched and adapted by the government of Uganda as a policy document for the protection of the rights of persons with albinism in Uganda.

The Organization participated in several commemorations including International Albinism Awareness Day, International Day of Persons with Disabilities (IDPD) where the Public Report on the situation of Persons with Albinism was launched by H.E Jessica Alupo (Major Rtd)

Albinism Umbrella also made efforts to give and amplify the voice of persons with albinism through lobbying for learners with albinism have been registered for large print font in National Examinations, extra time to write examinations, front seats in the classrooms. Outreaches to 7 schools were conducted to reach learners with information and services. Hard to reach communities were also reached with services and assistive devices such as sunscreens, binoculars, wide brimmed hats, sun glasses. There has been efforts to improve health care services in 5 health facilities using the community Score cards tools.

Several capacity strengthening interventions were implemented to improve lobbying and advocacy capacity of persons with albinism including; Self-awareness and Self-acceptance (SASA) and peer to peer group formation.

Networking was fostered through establishing an advocacy network on issues of persons with albinism. The network is comprised of 12 members from different organizations including the Equal Opportunities Commission, Ministry of Education and Sports, Barefoot Law, representatives from the refugee settlements, OPDs, rights holders from the health and business sector and the media.

A mini research was conducted in the districts of Kampala and Wakiso to identify the number of persons with albinism and assess the impact of COVID-19 to their lives.

The organisation continues to strengthen her institutional capacity through development of policies such as data protection policy and communication strategy. We also successfully conducted an Annual general meeting and trained board members on the Convention on Rights of Persons with Disabilities and Sustainable Development Goals

The accomplishments were possible through funding by a number of development partners including; Voice global and Disability Rights Fund, Aga Khan Foundation and Christian Blind Mission.

## CHAIRMAN BOARD OF DIRECTORS

It is another exciting time when we report to the AGM as a board. On my behalf and the entire board of directors of Albinism Umbrella, I wish to present to you the Annual report and some of the key milestones we made in the past year. My sincere appreciation to the entire team at the secretariat for the continued effort to steer the organisation.

During the recently concluded year, we were thrilled to launch the National Action Plan for Persons with Albinism becoming the third country after Mozambique and Malawi. This is Government commitment to persons with albinism and we should embrace it to actively be part of its implementation. Special thanks to the Ministry of Gender, Labor and Social Development for spearheading this fundamental milestone. We also concluded the spatial mapping with a total of 35 districts in the country digitally mapped.

2022 marked the end of the implementation of the Strategic Plan 2019-2022. We plan to undertake its review and development of the next plan in the year 2023 as we align it to the changing civic space in the country. We also hope to embark on solidifying our work through the creation of albinism groups at district level to build a strong network across the country. This is in line with the objective of improving livelihood

and at pinot national development agenda through the various programs like Parish Development model, Emyoga, Special grant etc. To this end, Christian Blind Mission is supporting a project in Kamwenge and Kyegegwa to create sustainable economic livelihoods. We also intend to venture into the preliminaries of local sunscreen production as a vital necessity for all persons with albinism.

I end by appreciating our development partners, who have continued supporting our programmes to reach out to the albinism community all over the country. We thank you for your continued partnership and support towards our work.

To my fellow board members and staff of Albinism Umbrella, I wish to encourage us to keep supporting each other as we endeavor to attain a dignified life.

Wishing you a great 2023.



**Simon Peter Okwi**  
*Board Chairperson*



## FORWARD BY THE EXECUTIVE DIRECTOR

Dear Colleagues,

Greetings from Albinism Umbrella,

As we reflect on our journey thus far, it has been amazing and hope to continue in this stride. Albinism Umbrella has now existed for 5 years and as an organisation, we believe we are able to serve our community more effectively and efficiently with renewed strength from the milestones achieved. Our Vision “A society in which persons with albinism are dignified and realize their full potential” is still relevant and are relentlessly pursuing it.

We are grateful to all the partners who have supported us in the many activities done in the past years. Most notably we can prove that we are creating some impact with more persons with albinism being able to speak for their rights. This is evidenced in the districts of Hoima, Buikwe, Luweero, Lira, Kamuli, Bundibugyo, Wakiso, and Kampala which took center stage in the year 2022 with various interventions. These particularly benefited from Self Awareness Self advocacy (SASA) trainings which boasted their self-esteem.

With the conclusion to the spatial mapping research across the country which also highlights the refugee community in Uganda, Albinism Umbrella is now well grounded to do evidenced based advocacy so as to implement the recommendations given to different stakeholders.

The National Action Plan for Persons with Albinism dubbed NAP, is a great milestone for Uganda as a country. Uganda is the 4th country in Africa to domesticate the

African Plan of Action on Albinism. (Plan of Action 2021-2031). The Government demonstrated support for persons with albinism by adopting this plan and we call upon you to come with us on this journey to freedom for persons with albinism.

In this year, our biggest dream is to make sunscreens regularly available to every person with albinism. This is indeed the desired state and we hope to start the journey into local sunscreen production. We welcome all partners to make this a reality. We are also keen to serve the more remote areas of Uganda and our sincere appreciation goes to Christian Blind Mission(CBM) for the opportunity to serve Kamwenge and Kyegegegwa in this year.

We cannot do without the support of our dear donors, Voice program has been immensely beautiful thus far, the Constellation team and the global team were so amazing with lots of learning from the continent. Disability Rights Fund, GIZ, Aga Khan foundation, we are grateful for the lives empowered.

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

Let us enjoy humanity together!



**Olive Namutebi**  
*Executive Director*



E: 03/12/2022

Persons v

JUST LIKE YOU

Addressing  
Myths and  
Misconceptions  
on Albinism

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## WHO WE ARE

Albinism Umbrella (AU) is a registered non-government organization that engages the community to reduce the vulnerability of persons with albinism, promoting and protecting their interest while preventing violation of their rights. It was formed with an aim to change the narrative about albinism, the wide spread discrimination and inhumane activities done against persons with albinism. As Albinism Umbrella, we amplify the voice of rights holders.



### OUR VISION

We want a society in which persons with albinism are dignified and realize their full potential.



### OUR MISSION

To promote and protect the rights of persons with albinism in Uganda through research, partnerships and advocacy for their improved wellbeing.

### Our theory of change

We acknowledge that persons with albinism suffer social exclusion. There are a number of challenges that characterize their situation including; unknown population of persons with albinism, stigma and discrimination, inaccessibility to health services, unconducive education environment and below the average living standards. Change for persons with albinism can be attained through; digital mapping of persons with albinism, group formation for rightsholders, advocacy skills training, measuring effectiveness of group performance and engagement in governance and public service accountability.

# OUR THEMATIC AREAS AND STRATEGIC OBJECTIVES



During the current 5-year Strategic Plan( 2019-2023), Albinism Umbrella has purposed to be a partner of choice for persons with albinism in Uganda, ensuring that their lives are protected, their livelihood supported and their dignity promoted. The organization continues to render services to vulnerable persons with albinism under the programme themes; Security, Health, Livelihoods and Social Justice.

**Each of the thematic arears contributes to Albinism Umbrella's strategic objectives namely;**

**To put persons with albinism's rights and well-being at the heart of policy makers.**

**To give a voice to persons with albinism.**

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

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

## WHAT WE ACHIEVED IN 2022

During 2022, Albinism Umbrella made great strides in promoting the rights of persons with albinism. We partnered with government, development partners, civil society to deliver interventions that address our key strategic objectives. In this section, we hereby share with us our key activities and how they are impacting the persons with albinism.





Hon. Laura Kanushu, National Woman Member of Parliament for Persons with disabilities while launching the report

## **STRATEGIC OBJECTIVE 1: PUT PERSONS WITH ALBINISM'S RIGHTS AT THE HEART OF POLICY MAKING**

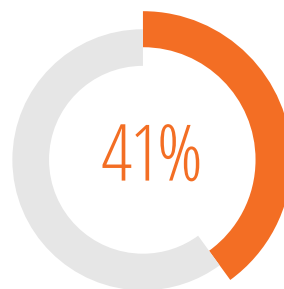
### **1. LAUNCH OF THE SPATIAL MAPPING REPORT ON PERSONS WITH ALBINISM IN THE WESTERN, NORTHERN AND CENTRAL REGIONS.**

Albinism Umbrella through her project "The Un known about Albinism" has continued to put persons with albinism at the heart of policy making through spatial mapping research. In 2021, spatial mapping was conducted in 25 districts of Northern, Western and Central regions of Uganda to profile and identify households of persons with albinism with support from the Voice project.

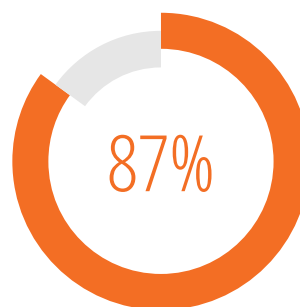
Albinism Umbrella successfully held a report launch on April 29<sup>th</sup> graced by Hon. Laura Kanushu-National Woman Member of Parliament for Persons with disabilities. The report was received as a significant tool to support advocacy for the inclusion of persons with albinism.

The spatial mapping exercise held this year adds to previous efforts by Albinism umbrella to undertake spatial mapping in other parts of Uganda including 10 Districts in three sub regions of Teso, Bugisu and Busoga.

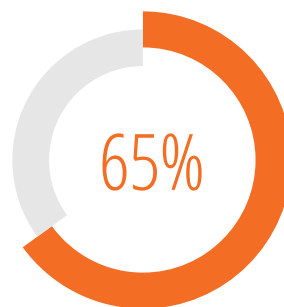
During the dissemination exercise, Ms. Olive Namutebi, the Co-Principal Investigator shared key highlights of the report. In her remarks she observed that there is fairly good community awareness and acceptance of persons with albinism although negative perceptions still prevail for instance 41% don't enjoy human rights. There are knowledge gaps about individual risk factors for persons with albinism for instance 87 percent didn't know that causes skin cancer. Access to health services is still low; 65 percent of those with eye problems had never accessed eye-check-up services and 80% do not have access to sunscreen.



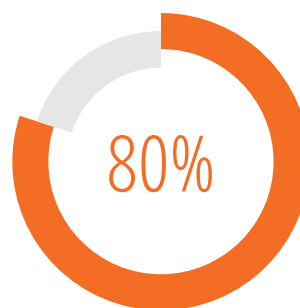
**Don't enjoy human rights**



**Didn't know that causes skin cancer**



**Never accessed eye-check-up services**



**Have no access to sunscreen.**

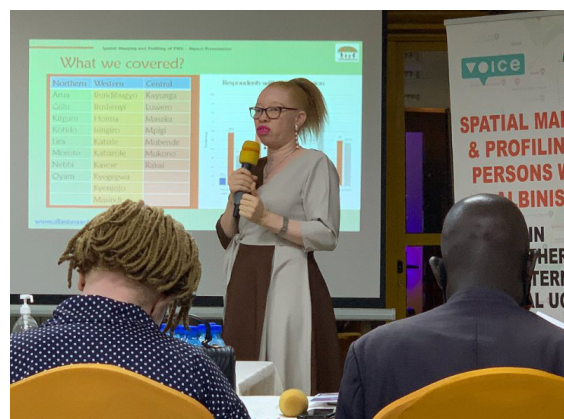


**For details refer to:** <https://albinismumbrella.org/wp-content/uploads/2021/12/Abridged-Version-of-Spatial-Mapping-Report-21-05-19.pdf>



Hon. Laura Kanushu National Women Member of Parliament-Persons with Disabilities officially launching the spatial mapping report

The Report was officially launched by the Chief guest Hon. Laura Kanushu National Women Member of Parliament-Persons with Disabilities. In her remarks, she applauded Albinism Umbrella for the research which has provided facts to support advocacy efforts. She also called on the need for implementation of disability laws and for persons with albinism to report cases of violation for legal action. Lastly, he called upon Albinism umbrella to organise their groups to benefit from the special grant for persons with disabilities and the Parish Development Model.



Ms. Olive Namutebi, the Executive Director and Co-Principal Investigator of the research presenting the key findings of the spatial mapping research.



## 1.2 REPORT LAUNCH AND DISSEMINATION OF THE RESEARCH ON REFUGEES WITH ALBINISM IN THE SETTLEMENTS OF KYAKA II, NAKIVALE AND RWAMWANJA

Similarly, on August 25th, a report on community perception on persons (refugees) with albinism living in the settlements of Nakivale, Rwamwanja, Kyaka II in the districts of Isingiro, Kamwenge and Kyegegwa respectively was launched with the objective to disseminate findings in the three settlements. The same intervention was carried out in Bidibidi settlement but findings show that there were no persons with albinism in that particular settlement.

Some of the key findings from the research include; stigma, fear and difficult livelihood as the major challenges affecting this community. In Nakivale, some protective measures such as sun screens are provided although the budget is small to procure for more and replace the worn out. The study recommends increased awareness within the community, and protection for persons with albinism. Service workers should prioritize persons with albinism while extending services to lessen effects from the sunshine since they keep in the lines for long hours leading them to self-medicate.

During the dissemination workshops, different recommendations on improving the state of rights holders in the settlements were made from the key stakeholders including; office of the prime minister, OHCHR, Police, Windle International among other organizations.



Official launch of the report on refugees at the Hilton Hotel, Kampala



Mr. Fidel Nelson (TAAF), Mr. Mugabe (OPM-Kyaka II), ASP Anatooli Muleterwa (UPF-CP) and Ms. Darlson Kusasira (OPM- refugee response) were the panellist as depicted in this Photo.



**For details refer to:** For details, refer: <https://albinismumbrella.org/wp-content/uploads/2023/01/Community-perceptions-towards-persons-with-albinism.pdf>

### 1.3 LAUNCH OF THE NATIONAL ACTION PLAN FOR PERSONS WITH ALBINISM((NAPPWA)

The National Action Plan for Persons with Albinism (NAPPWA) was launched and adapted by the government of Uganda as a policy document for the protection of the rights of persons with albinism in Uganda. The Action plan was launched on June 13th, 2022 by the State Minister for Disability – Hon. Hellen Grace Asamo at the commemoration of the International Albinism Awareness Day in Lira- Northern Uganda. The plan was successfully disseminated to different stakeholders both at National and regional levels to come up with an implementation plan. Different stakeholders made different commitments towards the cause. The NAPPWA stems from the regional action plan that was endorsed by the African Commission on Human and People’s Rights, European Union and the Pan African Parliament in 2017 as a policy document for the protection of persons with albinism.

Hon. Asamo Hellen Grace- State Minister for Disability officially launching the NAPPWA on June 13th, 2022 during IAAD celebrations in Lira city.



This plan consists of agreed principles for promoting and protecting the rights of persons with albinism in Uganda and covers the objectives and specific intervention measures. It is broadly categorized in eight (8) main principles which include; Inclusion and participation, Accessibility, Albinism mainstreaming, Equal opportunities and equal treatment, Financial security, Self-determination/independence, Self-advocacy and Awareness raising.

The was developed through a consultative process and input from key stakeholders including; the UN Independent Expert on the enjoyment of human rights by persons with albinism, National Council for Persons with Disability and validation process on October 28th, 2021 at the Kampala Sheraton Hotel.

On November 25th and December 8th, 2022, Albinism Umbrella organized dissemination workshops bringing together key stakeholders at regional and National level. The objective was to facilitate stakeholders understanding of the NAPPWA for effective use, buy-in, support as well as obtain suggestions for recommendations on mechanisms and strategies for its effective implementation. The workshops attracted 90 participants (47F,43 M) from Government Ministries, Departments and Agencies, Civil Society Actors, Development partners, OPDs, Media practitioners, rights holders among others who shared progress towards attaining the key targets and made commitments towards realizing the key intervention areas.



Dissemination workshop in progress



Executive Director and Board chairperson at the launch

## OUR ASK

Whereas the adoption and launch of the NAPPWA on Albinism constitutes a significant milestone in this extremely important journey, there is need for wide distribution, sharing and most importantly implementation in order to achieve its aims and objectives for the promotion and protection of human rights. Coordination across sectors and among stakeholders as well as sufficient financial support and adequate budgetary allocations are critical to the successful implementation of this NAPPWA. Collective efforts are required and all stakeholders are implored to ensure that there is collaboration to deliver on the important objectives of NAPPWA in order to enhance the rights of persons with albinism in Uganda.



### 1.4 COMMEMORATION OF THE INTERNATIONAL ALBINISM AWARENESS DAY - JUNE 13TH

We commemorated the International Albinism Awareness Day on June 13th, 2022 under the theme “United in Making our Voices Heard”. The Uganda commemorations were held in Lira City with the aim of addressing the key issues affecting the albinism fraternity through; creating awareness, ending violence and discrimination against persons with albinism, and advocating for their inclusion in the development processes. The event was officiated by the State Minister for Disability Affairs, Honourable Helen Grace Asamo.



During the commemoration, a series of events were carried out to ensure extensive community awareness about albinism ranging from radio talk shows, distribution of flyers with information about albinism, a peaceful match on the streets of Lira with a band and provision of health care services such as skin cancer screening, eye care screening provided by the eye department from Lira Regional Referral Hospital, distribution of sunscreens and donation of blood by Uganda Red Cross Lira blood bank. FIDA-Uganda provided a mobile legal aid service clinic for persons with albinism who had legal inquiries.

Pupils taking part in a peaceful march during international Albinism awareness day



Eye check-up services in progress

Persons with albinism participated in blood donation

Other key participants were; Mr. Robert Kotchani, the Country Representative of United Nations Office of the High Commissioner for Human Rights (OHCHR) in Uganda, representatives from Lira City, Uganda Human Rights, National Council for Persons with Disabilities, Ministry of Gender Labour and Social Development, representatives from the albinism fraternity organizations such as Uganda Albino Association (UAA), Source of the Nile Union for Persons with Albinism (SNUPA), Elgon Foundation for Persons with Albinism (EFPA), AIM among others, Rights Holders from the Northern Sub region and the general community.

The State Minister for Disability Urged the albinism fraternity to continue with advocacy beyond IAAD and keep reminding her Ministry on their needs throughout the year. She called for continuous support from

government and partners towards the implementation of the NAPPWA. Lastly, she urged parents and the general community to fight for the rights of the children with albinism

The Minister also noted that the policy on special needs education had already been cleared from the ministry of education, the certificate of financial implications had been granted and had now moved to the secretariat of cabinet. "I want to assure you that when it gets to cabinet, we shall still fight for it and ensure that it is cleared by His Excellence the president and it becomes operationalized to cater for special needs education." Said Hon. Asamo.

Guest of honor- State Minister for Disability Affairs Hon. Hellen Grace Asamo delivers her speech.



Persons with albinism and participants take a peaceful march through Lira city

*"I want to pledge that the few children who were here, if the IDPD is not celebrated in statehouse, if we are in Kololo- the teachers will organise those children, I personally will facilitate them to come to that venue and I will ensure that they sing before His Excellence the president so that when I advocate for free sunscreen provision, they act because they will have seen the need."* Said Hon. Grace Asamo



## 1.5 COMMEMORATION OF THE INTERNATIONAL DAY OF PERSONS WITH DISABILITIES ON DECEMBER 3RD IN KOLE DISTRICT AND THE LAUNCH OF THE PUBLIC REPORT ON THE SITUATION OF PERSONS WITH ALBINISM

Every year 3rd December, Uganda joins the rest of the world to commemorate the International Day of Persons with Disabilities (IDPD). The day aims to promote an understanding of disability issues and development, and to raise awareness of the situation of persons with disabilities in all aspects of political, social, economic, and cultural life. The theme for 2022 was “Leadership and Mindset Change: A tool for Inclusive Development.”

The commemoration was graced by H.E Jessica Alupo (Major Rtd) who in her speech observed that the celebration was aimed at having a 360-degree evaluation of how far the government and other stakeholders have gone as far as uplifting the lives of persons with disabilities in Uganda. She congratulated the disability movement on the launched tools on the audio visual, persons with disabilities act, braille version of the constitution, the revised national policy on persons with disabilities and the public report on the situation of persons with albinism and pledged her total

support towards implementation of the policies. Furthermore, she committed to ensuring that the inclusive education and the rehabilitation policies were to be approved and tabled to cabinet.

The event was significant to the albinism fraternity because it saw the official launch of the Public Report on the situation of Persons with Albinism by H.E Jessica Alupo (Major Rtd). The said report is aimed at raising awareness on albinism and highlighting ongoing challenges faced by persons with albinism in Uganda. It addresses myths and misconceptions around albinism that affect their enjoyment of human rights including the right to health, education and employment. It also gives an insight into societal discrimination experienced particularly by women and children with albinism and women who are parents, guardians and caregivers to children with albinism. Albinism Umbrella calls upon the general public to disseminate the report to create a society in which persons with albinism are dignified.

H.E Jessica Alupo (Rtd) officially launching the Public report on the situation of Persons with Albinism on 3rd December during IDPD commemoration in Kole District





## STRATEGIC INTERVENTION 2: TO GIVE A VOICE TO PERSONS WITH ALBINISM

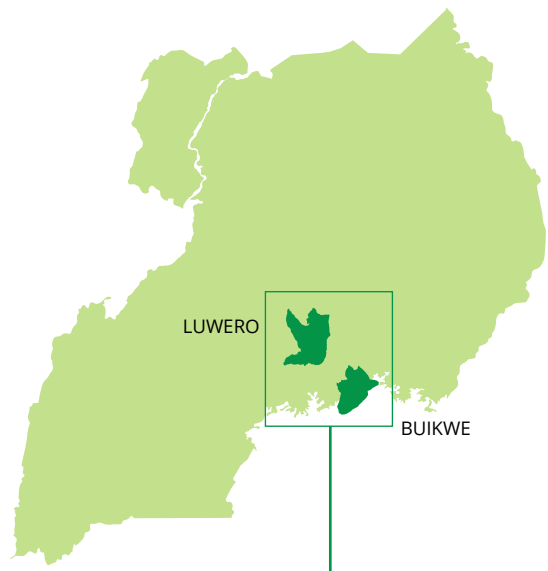
### 2.1 SUPPORT TO LEARNING FOR CHILDREN WITH ALBINISM

Albinism Umbrella works with partners to ensure children with albinism have access to quality education in their respective communities. Several efforts have been made in 2022 to keep children in school and enhance their learning experience.

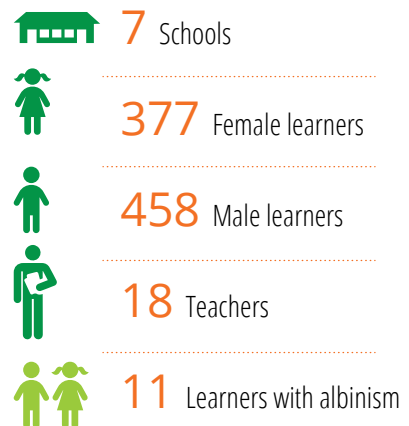


#### As a result of Albinism Umbrella's advocacy,

- Learners with albinism have been registered for large print font in National Examinations
- Given 30 minutes as extra time to write examinations
- Given front seats in the classrooms.
- Safe learning environment has been provided to facilitate their learning.



#### OUTREACHES



Ms. Olive Namutebi addressing pupils about albinism during a school outreach program in Buikwe District



Aide my education to brighten my future, eye sight services extended to the children



Creating awareness on albinism through community outreaches by the Albinism Umbrella team

### **The objectives of the outreaches were;**

- Improve students' level of awareness about albinism (intended to counter stigma and discrimination)
- Advocating for a safe learning environment for learners with albinism
- Extending eye care services (including checkups and assistive devices provision) to learners with albinism.

The ultimate aim was to contribute to reducing the dropout rates in schools caused by the un supportive learning environment. The school's sensitization strategy has a multiplier effect because information on albinism extends to parents through their children. Research shows that more than half of the people with albinism have only attained primary school education because most of them (75.7%) have an eyesight problem which has led to a high school dropout rate. The provision of eye care services is therefore a key priority for persons with albinism and during the school outreaches, this service was supported by Mengo Hospital. Following the school outreaches, reports from schools show that the learning environment for persons with albinism has improved.

Some of the key learning from the outreaches include; There is still a wide knowledge gap about albinism not only among students/learners but also among teachers. Stigma and discrimination still account to the high rates of drop out from schools by learners. Not so many teachers understand the learning needs of children with albinism, a call for increased awareness and sensitization in schools. Most learners have limited access to eye care services which is a bottleneck to their learning.



Sunscreen Distribution by the Albinism Umbrella team

## 2.2 INFLUENCING ACCESS TO SERVICES FOR PERSONS WITH ALBINISM

Albinism Umbrella through her project the “Un Known about Albinism” (supported by Voice global) committed to supporting rights holders in their efforts to influence access to social services, inclusive participation and in promoting social accountability. Having attained a bird’s view of the number of persons with albinism, where they are and their respective needs, we embarked on building their capacity in different aspects, focusing on a rights holders led approach to development.

### **Extending services to hard-to-reach communities**

Albinism Umbrella continued to take services closer to hard-to-reach areas to ease access to assistive devices (sunscreens, binoculars, wide brimmed hats, sun glasses) and

promote health. Over 11500, 200mls bottles of sun screens were distributed country wide either directly by Albinism Umbrella team or through our partners like OHCHR, FIDA-U, Mengo Hospital among others.

Through the Power to Us project, we reached out to 80 (57F, 33M) vulnerable persons with albinism with food relief packages in the districts of Kampala and Wakiso. This improved people’s lives and enabled them to meet their dietary needs. This was supported by the Aga Khan Foundation.

### **Improving the quality of services**

Community Score cards exercise was carried out in 5 health facilities; Katabi health center III (Entebbe-Wakiso district), Lira regional referral hospital (Lira district), Hoima regional



A rightsholder making a presentation during a Community Score Card exercise in Katabi Health Center III- Entebbe.

referral hospital (Hoima district), Wakisi health center III (Buikwe district) and Bugulumbya health center III (Kamuli district). Through the above exercise, health service providers and the community members discussed the quality of service from both a user and service provider perspective.

A Community Score Card (CSC) is one of the Citizen Led Accountability practices, a two-way participatory tool for the assessment, planning, monitoring and evaluation of services. It brings together the demand side (service user) and the supply side (service provider) of a particular service to jointly analyze issues underlying service delivery problems and find a common and shared way of addressing those issues.

The score cards were drawing from the findings from the spatial mapping and profiling of persons with albinism which showed that overall, 43.5% of persons with albinism had been rejected at different service points such

as hospitals, schools and other social services because they had albinism. The research also revealed that skin and sight challenges pose the greatest hindrance to living a dignified life and that 80% of persons with albinism succumb to skin cancer. Albinism umbrella obtained perceptions of persons with albinism and the general community in regards to health service delivery and quality. From the exercise, communities committed towards; improving supply of medicines in health facilities, recruitment of more specialists such as Dermatologists and ophthalmologists and reduce waiting time for persons with albinism.

### **Strengthening capacity of rightsholders in leadership and governance**

In a bid to enhance advocacy and governance, we built the capacity of rights holders in leadership and governance. These trainings were extended to 105 rights holders (71 Females and 34 Males)

in the 4 districts of Buikwe, Hoima, Kamuli and Lira with the objective to equip rights holders with leadership and governance skills. Participants were introduced to basics of understanding leadership, qualities of a good leader, what fails good leaders and governance. By the end of the training, rights holders were acquainted with basic knowledge and urged to participate in different leadership positions as this is a right that they need to exercise.

### **Self-awareness and Self-acceptance (SASA)**

Self-awareness and Self-acceptance (SASA) was another area where rights holders' capacity was enhanced. Self-acceptance defines awareness of one's strengths and weaknesses and allows one to accept their capabilities and feeling of satisfaction with own self despite of being aware of their inabilities. From the spatial mapping research conducted in 2021, stigma (self and society) and discrimination emerged as some of the most challenges faced by persons with albinism. This prompted Albinism Umbrella to introduce the concept self-awareness and self-advocacy (SASA) as a starting point in building their capacity.

The trainings were highly participatory and various training methods were used including presentations, group tasks that included working in teams to enhance critical thinking, decision-making, collaboration, and communication skills. Presentation by both the facilitator and participants were done to allow members become active participants in a training throughout all sessions. Each participant was given an opportunity to present or say a word which enhanced public speaking skills among rights holders. The SASA concept enabled members to become more aware of self. Participants identified activities to take forward as a means of boosting their self-advocacy as a group and these included, having family visits, awareness creation through lobbying for radio airtime, visiting schools and health facilities to create more awareness. Champions agreed to spearhead advocacy activities that the group members agreed to and this was a step towards empowering more persons with albinism to know their potential that the SASA trainings were creating. Self-advocates were groomed and nurtured to take part in and influence decision making process for the betterment of the albinism fraternity. We envisage that when rights holders' confidence and esteem is boosted, they are able to demand for their rights, speak about the injustices and advocate for safe spaces to have a dignified life.



Participants sharing ideas in their respective subgroups.



Group photo for participants after a workshop for peer to peer and group formation at Wakisi sub county in Buikwe District

## Peer to Peer Support and Group formation

With support from DRF, we organized rights holders in to peer to peer groups and orientated them on the group basics.

The activity happened at a time when the DRF team had visited Uganda for its grantee convening in May 2022 in Kampala. With a purpose to do a site visit and get the experimental learning from the community, the DRF team joined the Albinism Umbrella team on this particular activity whose objective was to identify and organize persons with albinism in peer-to-peer groups as well as orienting members about the basics of group formation and requirements needed. The workshop held at Wakisi Subcounty hall attracted 33 participants (17F, 13M) including rights holders, sub

county leaders, DRF and Albinism Umbrella team.

In a participatory session, Mr Hassan Mulondo in the picture above took members through what a group is, which size would work for them, the group composition, the existing government programs and the necessary requirements for registering with the local authorities. In their response, members requested to have a group of at least 10 members including persons with albinism (70%), parents/care takers of persons with albinism and persons with other disabilities. In addition, members requested that necessary documentation (e.g constitution, minutes etc) should be translated in local languages for easy understanding by members. While



concluding, members were encouraged to come up with a group name and select a committee which is trust worthy and committed.

The Disability Rights officer, Ms. Katiya Sakala was excited with what Albinism Umbrella had achieved so far and said that it was a great honor that the team from DRF was here to witness what actually happens on ground. "Reading reports on how the team mobilized members in this district and done community outreach in the other district is different from us coming on the ground to see who these members are, how do they form groups so that even when they give us proposals for funding and they budget for participants' re-imburement, group formation or registration, we understand because we have seen for ourselves and heard from the district leaders." Katiya added.

She said that having members on ground is one of the areas that makes Albinism Umbrella an umbrella it is and urged members to show their level of commitment or even move beyond a group and form their own organization. Ms Katiya added that in 1 or 2 years from then, she would want to witness a big group well established and would be happy to say yes, "I was there when they were forming this. "Once that happens, you can qualify to directly apply for grants from DRF even without going through Albinism Umbrella"

She encouraged members to work as a team, make use of the committed district leadership and wished them the best.

The activity saw the formation of a group, "Wakisi Albinism Group". The district leadership committed to support persons with albinism and to walk the journey with them right from group formation, registration to guiding them on the appropriate use of the grant. During the visit, over 60 bottles of sunscreens were delivered to persons with albinism in Buikwe district.



Mr Hassan Mulondo during the workshop



Ms. Katiya Sakala from DRF giving her remarks

## STRATEGIC INTERVENTION 3: BUILD A STRONG COMMUNITY OF PROFESSIONALS THAT PUT ISSUES OF PERSONS WITH ALBINISM WITHIN THEIR WORK

### 3.1 ESTABLISHED AN ADVOCACY NETWORK ON ISSUES OF PERSONS WITH ALBINISM.

Advocacy and partnerships are some of the channels to attain a dignified society for persons with albinism. With support from the Disability Rights Fund, Albinism Umbrella identified stakeholders and formed a National Advocacy network. The objective was to create a network of like-minded people that would amplify issues of albinism to bring about a positive change. The network is comprised of 12 members from different organizations including the Equal Opportunities Commission, Ministry of Education and Sports, Barefoot Law, representatives from the refugee settlements, OPDs, rights

holders from the health and business sector and the media.

In a discussion guided by a consultant, network members highlighted key areas of advocacy and presented them in a position paper. The paper entails the following;

- Government should invest in education for children with albinism as this population tends to have less access to education and employment thus experiencing entrenched poverty.

Group photo for the National Advocacy Network during a meeting held in Kampala





National Advocacy Network discussing the critical issues affecting persons with albinism

- Government should put in place a system charged with monitoring schools to ensure the environment is free of abuse and that students' health, education and social well-being is being looked after.
- Persons with Albinism should be helped to develop self-esteem to overcome stigma.
- Religious institutions such as the church and mosques should use the power and position it holds to deconstruct humanity issues.
- The general public should be sensitized on the fate of persons with albinism that they are natural human beings not to be used for rituals.
- Social workers should create awareness on the education of the general public on the importance of peaceful coexistence between persons with albinism and other people without albinism.
- Schools should teach children / pupils that hurtful behavior towards people with any sort of difference is a form of discrimination. A series of lessons on disabilities can provide information about albinism in the context of a variety of disabilities and other differences.
- Health social workers and allied health professionals must develop effective intervention programme to assist persons with albinism to develop self-esteem that will help them to overcome stigmatization
- As an integration measure and an ecological approach to inclusion, Youth involvement is paramount both at family and community level. This should ensure that challenges stemming from stigmatization and exclusion are curbed at a young age.
- All media encounters, especially health related engagements and campaigns, should be produced and strengthened to raise awareness about the condition and its stigma and to humanize and normalize albinism among family members, legal guardians, caregivers, youth, schools, labor organizations, communities, community leaders, the media and other civil society organizations.

## **STRATEGIC OBJECTIVE 5: TO BUILD AND STRENGTHEN THE CAPACITY OF ALBINISM UMBRELLA FOR INSTITUTION SUSTAINABILITY**

### **5.1 STRENGTHENED CAPACITY OF ALBINISM UMBRELLA AS AN INSTITUTION, BOARD OF DIRECTORS, STAFF IN ADVOCACY AND PROVISION OF STRATEGIC LEADERSHIP TO THE ORGANIZATION.**

#### **Development of policies**

Developed a communications strategy. The strategy contains relevant information to guide Albinism Umbrella team to communicate effectively among persons with albinism and the general public in efforts to promote the inclusion of persons with albinism in the society. After developing and validating the communication strategy, an orientation meeting for staff and board members was held at the Albinism Umbrella offices in Kampala. During the meeting, members were supported to understand the different components of the strategy and how it can be utilized to foster the work of Albinism Umbrella, they were equipped with some basic communication knowledge and skills such as an understanding public relation, behavior change communication, developing success stories, policy briefs, research briefs, among others.

**Data Protection Policy:** Albinism Umbrella developed a data protection policy to safeguard the Organisation's research, personal and programmatic data. The organisation is committed to handling of personal data in a manner that complies with data protection law and regularly reviewing it for responsible data protection practices.

#### **Successfully conducted the 2022 Annual General Meeting**

The meeting held on March 25th at Golf course Hotel-Kampala was the third of its kind with the objective of reviewing the 2020 Annual report, receiving and considering the annual audited reports as well as approving any amendments or alterations to the constitutions and minutes for AGM 2021. The tenure for members is still on thus, they all maintained their positions with Mr. Simon Peter Okwi as the Board Chairperson, Mr. Moses Mukuru-Vice Chairperson, Ms. Juliana Nantaba- Secretary



Edith Nantongo(left), Communication Consultant presenting the revised Albinism Umbrella Communication Strategy and orients staff on communication

and Ms. Brenda Boonabaana as the Treasurer. Other members include Dr. Isaac Kyazze, Ms. Barbra Anyinge and Ms. Isabella Akiteng.

### **Conducted a training on Convention on Rights of Persons with Disabilities and Sustainable Development Goals**

The secretariat and the board were trained in the concepts of CRPD and SDGs with a focus on Articles 5, 8 & 25, and goals 3, 4 & 10 respectively. The objective was to acquaint members with knowledge and information to promote advocacy for the inclusion of persons with albinism in education and health care services, enabling participants to recognize the linkages between the stated articles and goals, understanding their application to development contexts as well as supporting disability inclusion in the SDGs.

### **Advocacy Priorities for Albinism Umbrella**

The organisation has prioritized on the following areas for its advocacy agenda;

- Strategize on working with the Local Government in addressing issues of persons with albinism. For example, awareness raising during community activities, request for radio airtime from RDCs' offices.
- Engaging electoral commission on the needs of rights holders especially in regards to making ques under the sun while casting their votes.
- Engage cultural, religious institutions and other opinion leaders to support awareness creation about albinism. this will support in demystifying myths, cultural beliefs and misconceptions about albinism.

- Need to engage Ministry of Health on disability (albinism) identification and introduce stakeholders to an identification plan containing what should be done, the necessary care and attention to a child with albinism at birth.
- Finding out if persons with albinism can access cancer screening services on the medical insurance package.
- Engage Nursing institutions and medical councils to include topics on albinism in their curriculum
- Develop and update database on persons with albinism graduates and their qualification for easy follow ups and referrals to potential employers.
- There is need to carry out a census on learners with albinism in universities and higher institutions. This will enable in tracking and following up on those that get employed after finishing school.
- Engaging Albinism Umbrella communications team to create a portal on website where persons with albinism provide their information. This strategy will act as

continuous mapping.

### **Albinism Umbrella Partnerships and Resource Envelope**

Albinism Umbrella formalized its working relationship with the Ministry of Health to ensure quality, reliable and access to health care services to persons with albinism in Uganda. To ensure the implementation of the NAPPWA and inclusion of rights holders in different development processes, a MOU was developed and submitted to the MGLSD, pending approval from the Attorney General which we are looking forward to achieving in 2023.

In the year 2022, diversified efforts were employed in order to raise the funds to improve the effective service delivery of programs and to meet institutional costs. Voice global and Disability Rights Fund resumed funding the organizations through the Un Known about Albinism and the Advocacy for inclusion projects. Two new donors were brought on board that is to say the Aga Khan Foundation and Christian Blind Mission which led to the emergence of two livelihood projects.

## LINKING AND LEARNING

### **Linking and Learning program**

The Voice program was created to amplify and connect far unheard voices in efforts to leave no one behind. Stories of change are a powerful tool to package experiences of rights holders to not only enable them to reflect on their change stories but to also share these stories with others in their networks, and other external stakeholders. There are different types of change stories including; impact stories and success stories.

### **Linking with the Cheshire Services Uganda**

In March, the CSU paid a linking and learning visit to Albinism Umbrella. The organization is implementing a Girls Education Challenge Transition” project that focuses on empowering children with disabilities for independent living and building individual self-reliance. To facilitate networking and information sharing, CSU connected teenagers with albinism and their caregivers with Albinism Umbrella, a national body that uplifts the rights of persons with albinism.

During the engagement, the Executive Director Albinism Umbrella unpacked albinism, highlighting

what it is, what it is not, health issues, myths and misconceptions, learning environment and the available statistics. In a one on one interaction and group sessions, learners and parents were attached to role models who shared their success stories and were also given platform to share their stories of change. Eye care services like awareness, screening, distribution of binoculars, wide brimmed hats were done extended by Mengo Hospital.

### **Linking with the Voice global grantees.**

In September 2021, Voice introduced an online Livening the Linking and Learning program with the purpose of facilitating learning for all its grantees under her program “From Open to Inclusive Governance” with the best practices to successfully implement their respective projects and to ensure that they meet their set objectives. In September 2022, a 3 days in person workshop on “Deepening our Learning for Citizen Led accountability and Inclusive Governance”, a core activity of citizen led accountability was organized to facilitate learning, knowledge exchange and assess LLL program progress. This took place at Imperial view Hotel-Entebbe.

## Among the key learnings were

- Citizen Led Accountability practices
- Communication especially on how to tell stories using creative communication (audio, video, digital) and dissemination (traditional, social and mass media)
- Evidence based advocacy (by and with rights holders) how to engage duty bearers, nurture champions, shift attitudes and effect change
- Facilitation/ adult education; how to be an effective facilitator/adult educator, facilitate learning for CLA
- Grassroots empowerment; to enhance rights awareness, CLA and leadership skills of rights holders' communities
- Scale and sustainability; strategies for scaling up and sustaining project coverage and impact
- Coalition building; how to promote collaboration amongst projects and coalition building (with likeminded groups)

During the 3 days' workshop, Albinism Umbrella was delighted to practically lead the learning on Community Score card as one of the CLA practices

### **Outcome harvesting workshop in Dar es Salaam**

Among the various Voice grantees, Albinism Umbrella has progressively gained recognition and been nominated to different platforms to showcase her success stories and some of her best practices that influence impact. In August 2022, Ms. Olive Namutebi, our Executive Director was one of the participants selected to share some of the

significant Voice project outcomes during the outcome harvesting workshop organized by AAN in Tanzania. Documenting various changes along the change path is one of the key lessons learnt to improving project implementation.

### **Attended the 3rd African Dermatologists Conference.**

In the quest for local sunscreen production, Albinism Umbrella has been and is deliberately mapping out strategic networks and approaches which prompted her to participate in the 3rd African Dermatologists Conference organized by Foundation Pierre Fabre in Abidjan- Ivory



Coast. While in the conference, the Executive Director was able to learn about tele- dermatology and its applicability in Uganda and also learnt the best practices from partners that had sunscreens locally produced in their countries. Other than this, many engagements have been made and stakeholders brought on board to ensure that this initiative is brought to reality.

### **Celebrating our milestones**

July 25th 2022 marked exactly five years since Albinism Umbrella started its operations. In amidst

a number of partners and well-wishers from OHCHR, CBM, Barefoot Law, MOH, ABILIS Foundation, GIZ, Members of Parliament, Oxfam, rights holders, Albinism Umbrella Board, EOC among others. The Executive Director highlighted the achievements made in the 5-year period, the stories of change, success and learning areas and gave a snapshot about where the organization is heading. She warmly extended her appreciation to donors and partners who had walked the 5- year journey with the organization and called upon more to come on board in advancing the rights of persons with albinism.

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### **Conclusion**

Persons with albinism are a part of the society and the diversities therein. Any violation or abuse of rights affects the general humanity, their special needs especially in respect to health, education, personal security and livelihoods ought to be acknowledged by society and tackled. Albinism Umbrella is using all available platforms to challenge the current status quo of persons with albinism; stigma and discrimination, barriers to access to justice, poor access to social services. We call upon government and its partners to appreciate the urgent need for sustained awareness raising and intervention into their health, education and security concerns and to assure persons with albinism of their socio-economic and political rights as human beings. As a journey of a thousand miles starts with a step, Albinism Umbrella has already taken its first step in creating a deserving environment where persons with albinism enjoy all rights and freedoms enjoyed by all.

## ALBINISM UMBRELLA TEAM 2022



*From left: Doreen Nakuti- Monitoring and Evaluation Officer, Nicole Phiona Nantaba- Project Officer, Olive Namutebi Executive Director, Janepher Nanyondo- Program Officer, Henry Mujuni, Finance and Administration officer and Ivan Kagudde- Volunteer*

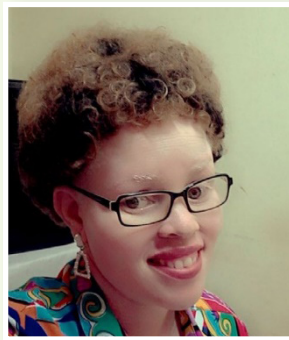
## BOARD OF DIRECTORS



**Simon Peter Okwi**  
*Chairperson*



**Moses Mukuru**  
*Vice Chairperson*



**Brenda Bonabana**  
*Treasurer*



**Juliana Nantaba**  
*Secretary*



**Isaac Kyaze**  
*Member*



**Isabella Akiteng**  
*Member*

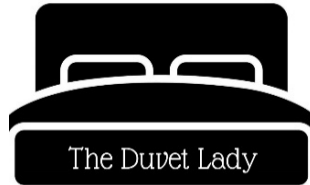


**Barbara Anyinge**  
*Member*



## DEVELOPMENT PARTNERS

As Albinism Umbrella aspires to deepen its impact, partnerships are core to our work. We seek to collaborate and advocate for an inclusive and dignified society for persons with albinism in Uganda and beyond. With our 5 years existence and experience working with different communities in Uganda, we have built strong partnerships with the government, International Agencies, Civil Society Organisations, partner NGOs, and the communities in which we work. We do acknowledge and express appreciation to our partners listed below for their continued commitment to enhancing the rights of persons with albinism.



# FINANCIAL REPORT

## STATEMENT OF INCOME AND EXPENDITURE

Particulars	Note	31-December-2022 Ushs	31-December-2021 Ushs
<b>Income</b>			
Grants income	2.1	656,879,643	488,202,827
Other income	2.2	156,310,000	22,038,100
<b>Total</b>		<b>813,189,643</b>	<b>510,240,927</b>
<b>Expenditure</b>			
Program Expenses	2.3	365,539,963	276,210,949
Staff costs	2.4	136,996,640	128,263,160
Administration costs	2.5	40,519,367	45,394,681
Finance Costs	2.6	1,768,237	2,050,336
<b>Total</b>		<b>544,824,206</b>	<b>451,919,126</b>
<b>Surplus for the year</b>		<b>268,365,436</b>	<b>58,321,801</b>

## STATEMENT OF FINANCIAL POSITION

Particulars	Note	31-December-2022 Ushs	31-December-2021 Ushs
<b>Assets</b>			
<b>Non-Current Assets</b>			
Property and equipment	2.7	72,039,150	387,500
<b>Current Assets</b>			
Cash and Cash Equivalents	2.8	352,400,251	157,345,794
Advances	2.9	-	1,330,000
		352,400,251	158,675,794
<b>Total Assets</b>		<b>424,439,401</b>	<b>159,063,294</b>
<b>Reserves &amp; Liabilities</b>			
<b>Reserves</b>			
Accumulated Fund		414,121,570	145,756,134
<b>Current Liabilities</b>			
Trade and other payables	2.10	10,317,831	13,307,160
<b>Total Reserves and Liabilities</b>		<b>424,439,401</b>	<b>159,063,294</b>





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