



ALBINISM UMBRELLA ANNUAL REPORT 2021



Executive Director's Foreword



Dear colleagues,
I am excited to share with you our 2021 performance. It was a challenging year with the Covid-19 disruptions but we managed to register progress.

The Covid-19 lockdown between May and August 2021, disrupted the planned activities particularly the community interventions. Nevertheless, we adapted and adjusted our programmes to new work styles where we used online tools to hold meetings, phone call interviews with community leaders for our mini- research and door to door distribution of sunscreens to rights holders around Kampala Metropolitan area.

Upon partial reopening of the country, we embarked on the field data collection on persons with albinism in the 25 districts in Central, Western and Northern regions. Field data collection was a success, report validation workshops were conducted across the three regions and the report will be launched in 2022.

We appreciate our development partners particularly the Voice Programme for providing financial resources that have facilitated the organisation to remain relevant in addressing the needs of persons with albinism. We also applaud the partners who have supported us with trainings in advocacy, CRPD and SDGs, governance, resource mobilization, leadership among others.

In the year we celebrate the partnership with Christian Blind Mission (CBM) which focuses on enhancing the livelihood and promoting eye health. At national level, we formalized our membership with National Union of Disabled Persons of Uganda (NUDIPU) to have a stronger advocacy voice. In addition to our voice of promoting and protecting the rights of women and children with albinism, we entered in to a collaboration with FIDA Uganda.

In addition, we are glad to note that Albinism Umbrella registered an increase in its staffing by recruiting a Monitoring and Evaluation officer.

I commend our Board of Directors and staff for the unwavering support and commitment towards the achievements registered in 2021. We are also grateful to our development partners for the technical and financial support rendered to the organization.

A handwritten signature in black ink, appearing to read 'Olive Namutebi'.

Olive Namutebi
Executive Director

Chairman's Comment



I am pleased to provide this comment on behalf of the Board of directors for Albinism Umbrella. It is with great pleasure that I present to you the annual report for 2021 while extending my appreciation to the secretariat for the continued effort to steer the organisation. As with 2020, this year saw the highest impact of the pandemic with many lives lost and our sympathy to each one of you who lost loved ones during this period. Albinism Umbrella was able to provide sunscreen to some members in the Kampala Metropolitan during these hard times as a health measure to protect against skin cancer.

During the year, as a board we focused on increased institutional strengthening, building partnerships and remaining relevant to the community we serve. I am pleased to announce that we were able to get strategic partners like Christian Blind Mission(CBM), FIDA Uganda and we appreciate the others who have continued to support our work. We faced some challenges when the Chairperson Ms. Allen Bonabaana stepped down to concentrate on other duties. Dr Isaac Kyaze and I were elected as a Board Member and Chairperson respectively at the last Annual General Meeting.

Albinism Umbrella managed to hold the International Albinism Awareness day in December as it was impossible to have it in June due the lockdown. With support from Ministry of Health we were able to provide an opportunity to the participants get vaccinated against COVID-19 during this event.

In a special way, we applaud the Ministry of Gender for validating the National Action Plan on Albinism and hope that it will be adopted for implementation. Our appreciation goes to all people who made irreplaceable contributions that made it possible to achieve these strides.

To our development partners, particularly the Voice Programme, 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 friendship to facilitate our work.

To my fellow board members and staff of 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 in the various responsibilities they undertake.

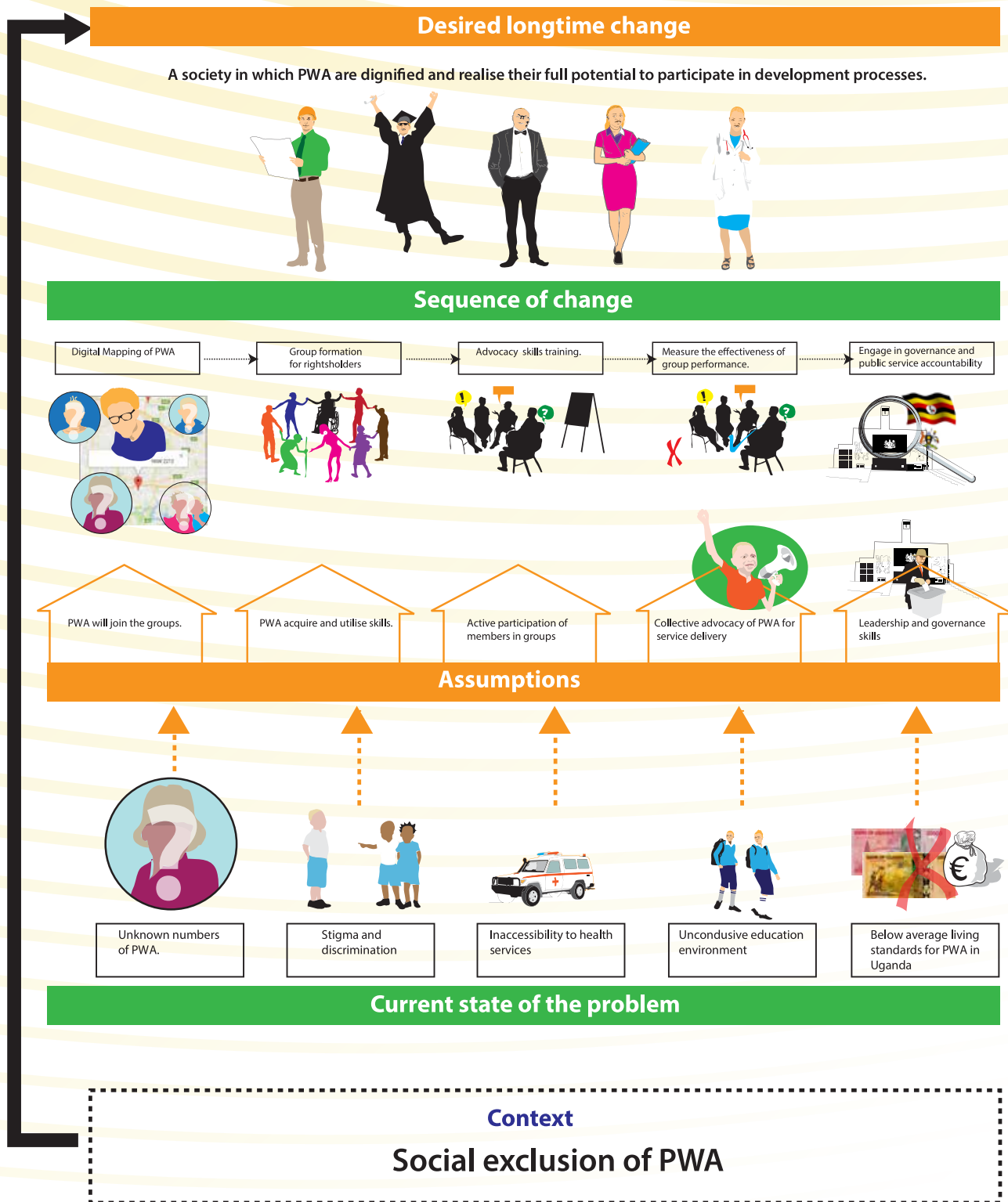
Let us make albinism more visible and together we contribute to a “Society in which people with albinism are dignified and realize their full potential.”
Enjoy the report.

Simon Peter Okwi
Board Chairperson

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Albinism Umbrella's Theory of Change





BACKGROUND

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, amplify their voices and further to empower them to fully engage in social-economic activities that directly improves their living conditions.

Organizational tenets

Our Vision

We desire a society in which people with albinism are dignified and realize their full potential.

Our Mission

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

Our objectives

» 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.
- » To build and strengthen albinism Umbrella for institutional sustainability.

Our Niche

- » Security
- » Health
- » Social Justice
- » Livelihood





Person with Albinism participates in a Spatial mapping of persons with albinism in Luwero District

OUR WORK

I. Research

We believe that creating public awareness is one of the mechanisms to address the common struggles faced by persons with albinism including stigma, discrimination, myths as well as the community exclusion. However, to understand the issues deeper, disprove myths and amplify the truth about albinism, there must exist concrete data and facts through research. At Albinism Umbrella, we have interested ourselves in research and have carried out spatial mapping profiling of rights holders, stakeholders and duty bearers with funding from Oxfam- Novib through the Voice program with the aim of;

- » Establishing the total number of persons with albinism in Uganda.
- » Mapping out service providers in respective areas.
- » Assessing community perception towards persons with albinism.
- » Constructing a model of group support for persons with albinism based on their views.

- » Advocating for access to services and inclusion of persons with albinism in mainstream development processes in Uganda.

Our research work involves the active participation of persons with albinism as the slogan states; “Nothing for us without us”. Through research, persons with albinism participate in mapping the different stakeholders such as district and community leaders who provide relevant information for the program and create awareness about albinism.

II. Health care



Affordable health care should be available to everyone, irrespective of gender, disability, learning requirement and socio-economic status. Albinism Umbrella addresses sight problems and skin complications among persons with albinism through the following interventions;

- » Fundraising for sunscreen and protective wear such as wide brim hats, binoculars and sun glasses
- » In collaboration with schools, communities, health centers, outreaches and training are done for teachers, parents and health workers on the needs of persons with albinism and how to relate



Children with albinism holding sunscreen bottles provided by albinism umbrella

with them when accessing services In order to render the health support to our persons with albinism, we have harnessed partnership with several organisations such as; African Albinism Association which supplies sunscreens, Mengo Hospital- Eye department that offered eye checkups, camps, assistive devices; Rotary clubs and United Nations Human Rights that has supported door-to-door sunscreen distribution.

III. Advocacy

Through advocacy, we engage policy makers within government, stakeholders and citizens to foster accountability on human rights policies and laws for persons with albinism.



Persons with albinism speak out about their rights during the International Albinism Awareness day commemoration

We also address stigma and discrimination which are deep-rooted causes of low self-esteem for persons with albinism. We also encourage family and community to accept persons with albinism and to support them for lasting change.

We have also centered our advocacy on accessibility of services such as education, health and legal protection to create an enabling environment for persons with albinism to thrive.

Advocacy is delivered through;

- » Creating awareness about albinism and issues that affect the community.
- » Engaging duty bearers on reasonable accommodation like tax waiver for sunscreens, provision of large print examinations for learners with albinism.
- » Fundraising towards the construction of a rehabilitation center for persons with albinism.
- » Engaging the government on the National Action Plan on albinism.
- » Extending relief items (food and other in-kind donations) to rights holders in times of need.

We work with Ministry of Gender Laboury and Social Development, Ministry of Health, Ministry of Education and Sports, the parliament of Uganda, UN Human Rights, Open Society Initiative of East Africa and organisations of persons with disabilities to have an amplified voice.

IV. Legal support



Disseminating Brochures to the police to understand the rights of persons with albinism

Persons with albinism must have equal opportunities just like any other human beings which calls for equal access to services such as legal protection. The disability movement has highlighted the impact of socioeconomic disparities and other forms of inequalities that affect persons with disabilities' access to legal support.

People with albinism continue to face exclusion from available social services and opportunities including employment due to stigma and discrimination and an

exclusionary environment that includes physical and structural barriers.

Albinism umbrella is fighting to ensure that its rights holders exercise their rights as citizens of equal value and status through;

- » Developing strong partnerships and linkages with legal focused organisations whose services we extend to rights holders. These include legal and human rights awareness training to communities.
- » Extending counseling and guidance in regards to the law.
- » Managing an online system where cases are reported for legal engagements and advice from a legal officer.

To fulfil our legal support, we are working closely with the Equal Opportunities Commission, the Barefoot Law and FIDA Uganda.



2021 IN REVIEW

This section highlights our 2021 story of how we have made a difference among persons with albinism and the communities we work with. It also reveals our efforts in building the rights and resilience of persons with albinism amidst the devastating effects of COVID-19. Most of all, it tells the story of how a global network of committed donors, partners, supporters, staff and well-wishers is striving to improve the lives of the albinism community. The COVID-19 pandemic led to a momentous change for us internally (both negative and positive) and that enabled us to evolve into a stronger, better and more inclusive organisation. We plan to incorporate what we have learned in to our 2022 programmes for a better Albinism Umbrella.



Our operational response to COVID-19

The COVID-19 lockdown between May and August 2021, disrupted the planned activities particularly the community interventions. Nevertheless, we adapted and maintained the positive impact of our programmes. We used online tools to hold meetings, phone call interviews with community leaders for our mini- research and door to door distribution of sunscreens to rights holders around Kampala metropolitan area.

As the lockdown was lifted, we highly encouraged our staff and rights holders to observe the standard operating procedures set by the government during physical engagements and activity implementation.

Progress towards strategic objectives

Despite the challenges caused by the COVID-19 pandemic, Albinism Umbrella made significant accomplishments in meeting the needs of persons with albinism in the various operational areas.

Below is a summary of the key achievements under each of her strategic objectives;

Strategic objective	What we did.
1.Put persons with albinism’s rights and well-being at the heart of policy making	We reached 134 stakeholders through advocacy meetings in central and Northern regions. The objective was to highlight the plight of persons with albinism and assess their perception towards this group. As a result, district leaders committed to advocate for inclusion and sensitization of the community about albinism and the how to support persons with albinism in their communities.
	The COVID-19 travel restrictions limited access to sunscreen by persons with albinism. Albinism Umbrella, with support of UN Human Rights Office made sunscreen accessible to persons with albinism particularly the most vulnerable. The door-to-door distribution of sunscreen lotions reached 53 persons with albinism.
	Albinism Umbrella spearheaded the validation of the National Action Plan on Albinism. The steering committee chaired by the Executive Director-Albinism Umbrella invited the key stakeholders and Ministry of Gender Labour and Social Development (MGLSD) to forge a way forward towards finalizing the plan. These efforts resulted into the passing of the plan whose launch is planned for 2022.
	As part of our spatial mapping research, we conducted validation meetings and shared research findings with 117 stakeholders, particularly at the district level. These included Community Development Officers, Inspector of Schools, Health workers among others. Recommendations and commitments were made in line with promoting awareness about albinism. This platform was also useful in advocating for improved service delivery for persons with albinism based on facts, we presented and shared
	We commemorated the International Albinism Awareness Day with an objective to create awareness and advocate for inclusion of persons with albinism in development programs. The recommendations and commitments made by duty bearers gave us hope in the quest for inclusion of persons with albinism. Albinism Umbrella also participated in the celebration of the International Day of Persons with Disabilities officiated by the President of Uganda at state house Entebbe under the theme “Not all disabilities are visible”.
	In a bid to provide basic necessities of life to our beneficiaries, we sought for support from well-wishers and distributed duvets, clothes, food, facemasks to over 70 persons with albinism.

<p>2. Giving a voice/ amplifying the voice of persons with albinism</p>	<p>We conducted 3 trainings on Convention on the Rights of Persons with Disabilities, Sustainable Development Goals and advocacy among staff, board and regional members. The training aimed at equipping them knowledge and advocacy skills to effectively negotiate with government and other policy implementers regarding inclusion of persons with albinism in mainstream development processes. This was made possible by Disability Rights Fund.</p>
<p>3. Build a strong community of professionals that put issues of persons with albinism within their work.</p>	<p>We entered into partnership with Christian Blind Mission (CBM) to improve the quality of life of persons with albinism through their programmes like Inclusive Eye Health, Community Based Inclusive Development and Disability Inclusive Development.</p> <p>We also partnered with FIDA and NUDIPU to enhance access to justice for women with albinism, promoting gender equality and women’s human rights as well as to have collective advocacy and an amplified voice for inclusion of persons with albinism.</p>
<p>4. Developing the local persons with albinism network in order to deliver a powerful force for change</p>	<p>We carried out spatial mapping and profiling of persons with albinism in the regions of Central, West and North. This is a great milestone to us for it provided the country representative data and will act as a basis for advocacy and access to services.</p>
<p>5. To build and strengthen the capacity of AU for institution sustainability</p>	<p>Policies like Human Resource, Safeguarding, Finance manual, Board Charter among others were reviewed and approved by the board. These are operational in implementing program work.</p> <p>In 2021, we focused on promoting visibility of our organization programs and activities. We created content for our social media platforms like Twitter, Facebook, YouTube, LinkedIn, Instagram and others. Radio and TV talk shows have also been part of our approaches to create visibility and awareness about albinism. This has enhanced information and knowledge sharing and it is changing community attitude towards persons with albinism.</p> <p>We held an Annual General Meeting in fulfillment of constitutional requirement of availing members with an update on the achievements and operations of an organization. In the same meeting, a new board chairperson and member were elected.</p>

Commentary of our program activities



Spatial mapping and profiling of persons with albinism in Central, Western and Northern Uganda.

This project contributes to Albinism Umbrella’s strategic area 4 which looks at developing a local network of persons with albinism in order to deliver a powerful force of change.

The “Un Known about Albinism” project focuses on profiling and mapping households with Persons with Albinism and using this data to form groups as a basis for advocacy and access to services. The initiative is a continuation of the mapping that was carried out in 2018 in 10 districts of Eastern Uganda with support from Oxfam Uganda through Voice under the Innovate and Learn grant. On learning about how innovative and successful the project was, Voice-global through its “From open to Inclusive Governance” grant has supported mapping in 25 districts in the central, western and northern regions hence attaining a country representative data on persons with albinism based on facts and credibility.

The table below shows the districts that were covered in respective regions.

Central Region	Western region	Northern region	Eastern region
Kayunga	Bundibugyo	Arua	Budaka
Luwero	Bushenyi	Gulu	Bududa
Masaka	Hoima,	Kitgum	Butaleja
Mpigi	Isingiro	Kotido	Buyende
Mubende	Kasese	Lira	Manafwa
Mukono	Kyegegwa	Moroto	Mayuge
Rakai	Kyenjojo	Nebbi	Kamuli
	Kabale	Oyam	Kumi
	Kabarole		Sironko
	Masindi		Soroti.

Prior to data collection, stakeholders’ engagements were held to inform stakeholders of the project’s objectives and overall contribution. 134 participants from government bodies, Office of the High Commissioner for Human Rights (OHCHR), Civil Society Organisations, District Police offices, districts local government (including Community Development Officers, District Health Officers, Inspectors of schools, District Union), religious, cultural leaders and persons with albinism were reached out to.



Left: Participants’ in stakeholders’ engagement meetings for Central (Fairway Hotel-Kampala).

Right: Northern (Tasha Hotel- Lira) regions respectively.

This research conducted between August and September 2021 was a cross-sectional study that employed both quantitative and qualitative methods, using snow ball sampling to reach out to rights holders. Spatial mapping of persons with albinism was done using tablets fitted with ODK software which had the ability to collect GPS co-ordinates as well as other data that was required for the study.

An interview guide was used to gather community perceptions about persons with albinism. This process included capturing pictures, case studies, and quotes from the participants.



In the pictures above, research assistants collect data from households of persons with albinism in Kabale and Luweero respectively.

Albinism Umbrella carefully selected and trained a team of field research assistants, with priority availed to persons with albinism to enhance their research competences.

The research assistants conducted in-depth interviews with Persons with Albinism, held focus group discussions with communities in which persons with albinism live and explored perceptions of key informants towards persons with albinism which was conclude by September 30, 2021.



Summary of the key issues highlighted by spatial mapping research-2021

- » Most parents (58%) of children with albinism and (57%) of children with albinism were from the central region.
- » Across the three regions, 48.9% of the respondents had primary level of education followed by 26.2% with secondary education.
- » 70.3% of all respondents across the three regions did not know the cause of albinism.
- » 72.8% of all persons with albinism across the three regions did not have easy access to sunscreen while 80.4% had problems with the eyes. In all, 70% of all the persons with albinism had never gone for an eye check up by the time we conducted the study.
- » The richest and poorest households of Persons with Albinism (based on the Gramin Poverty Index) were found in the Northern region.
- » The two main themes that emanated from the study were vulnerability of persons with albinism and Stigma arising from societal myths and misconceptions.
- » 48.5% and 41.3% of the respondents in the central and western regions felt that persons with albinism do not enjoy equal rights like other PWDs. Very few people in the Northern region at 16.3% had similar feelings.
- » As far as protection of rights of persons with albinism were concerned, only 57.1% of the respondents in the Northern region felt that the rights of persons with albinism were protected, only 28.5% in the central region and 47.8% in the western region shared similar feelings.
- » Distances travelled by persons with albinism to service points are of paramount importance because they highlight the plight of persons with albinism. Research shows that persons with albinism travel 18km in the northern region, 16.6km in the central region and 17.8km in the western region to access services from organisations that deal with persons with albinism.



Recommendations

- » ensitize communities where persons with albinism live and spelling out the causes of albinism, causes of skin cancer and how to prevent.
- » Persons with albinism need to be supported to acquire protective gear such as; clothing, glasses, caps and sunscreen. it is envisaged these will control harmful ultraviolet rays from reaching their skins.
- » Group formation among persons with albinism to promote their livelihood and strengthen their capacity to advocate for their rights.
- » Encourage caregivers and persons with albinism to continue with further education beyond primary level for better outcomes.



Dr. Arthur Bagonza - the lead researcher making a presentation of the findings during report validation in central region.

- » The government should waive taxes and offer outright exemptions on sunscreen used by persons with albinism. This will help to make the sunscreen more readily available thus offering a more sustainable supply.
- » To advocate for improved service delivery for persons with albinism based on facts, we presented and shared the research findings to stakeholders in their respective regions who gave their feedback and made commitments in the same validation meetings.



Group photos of stakeholders that attended the spatial mapping research-report validation in the Central, Western and Northern regions between November and December 2021.



The following lessons have been learnt during project implementation.

- » Inclusion of rights holders in direct project implementation is key to achieving the set objectives. We successfully identified, trained and deployed 90% of persons with albinism as field research assistants. This empowered them with knowledge and experience in carrying out research, but also manage safety issues and confidence among persons with albinism participating in the study to freely share their experiences.
- » Dialogue between rights holders and duty bearers shapes the nature of service delivery offered to persons with disability. These engagements have made known the plights of persons with albinism to duty bearers and this have enabled proper planning and inclusion of needs for persons with albinism in health, education and legal sector.
- » Collaboration and working in alliances promote collective effort geared towards enhancement of rights of persons with albinism. Our collaboration with the Prime minister's office enabled us to obtain clearance to interact with persons with albinism in refugee settlements. As a result, we have extended services such as sunscreen to the settlement but also got to know their perceptions and issues affecting them.
- » Continuous advocacy is key to achieving the desired impact. This is evident with the implementation of commitments by stakeholders e.g., provision of district airtime to create awareness about albinism.
- » Putting in place mechanisms that will absorb the identified and profiled rights-holders to participate in community programs is necessary. Many persons with albinism are yearning for an opportunity to be visible but lack the mentorship system and opportunity to tap this potential. Self-advocacy is equally possible once persons with albinism are empowered and shown the way to do it.
- » Continue to strengthen our program data capture, evidence and learning processes such that this collection/evidence base translates into programme design, implementation, and adaptation, as well as influencing policies about albinism.



Report validation meeting on the National Action Plan on Albinism

The National Action Plan on Albinism (NAP) is one of the tools that focus on placing persons with albinism's rights and well-being at the heart of policy making.

The National Action Plan (NAP) on albinism 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.

This plan on action came in to force after numerous atrocities were done against persons with albinism in various parts of Africa. It 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 plan has gone through several discussions with input from the UN independent expert on the enjoyment of human rights by persons with albinism, National Council for Disability and other development partners.



Group photo of stakeholders that participated in the validation meeting for the NAP at Sheraton Hotel-Kampala

On October 28, 2021, the National steering committee for the development of the plan chaired by ED-Albinism Umbrella' pooled together stakeholders to validate the plan, seek specific guidance from Ministry of Gender, Labour and Social Development on how to make it a reality as well as to concretize needs, priorities and strategic interventions for the albinism community. The meeting was graced by the presence of Honorable Asamo Hellen Grace-Minister of State for disability.

Key highlights from the meeting



Mr. Robert Kotchani-OHCHR giving his remarks during NAP validation meeting

Mr. Robert Kotchani- OHCHR Uganda Country Representative commended Uganda for the significant efforts in addressing discrimination against persons with albinism for example by recognizing albinism as a form of disability in the 2020 Persons with Disabilities Act.

It was noted that persons with albinism in Uganda remain a marginalized group subjected to human rights challenges like stigma, myths and

misconceptions which has exposed them to discrimination and violation of their rights.

The UN human Rights Office in Uganda has been working with several members of the albinism community, the Equal Opportunities Commission (EOC), the Parliament of Uganda and other partners to raise awareness about the challenges faced by persons with albinism through extending support in the commemoration of the June 13, International Albinism Awareness Day and by carrying out advocacy activities against stigma and discrimination.

There is a Situation Analysis Report on human rights challenges of persons with albinism in Uganda which identifies some key challenges affecting the albinism community and makes recommendations to support planning and design of effective strategies for addressing those challenges.

According to Hon. Shifrah Lukwago-Uganda Human Rights Commission, the International Convention on Civil and Political Rights (ICCPR), the International Convention on Economic Social and Cultural Rights (ICESCR), the Convention on the Rights of the Child (CRC), the Convention on the Rights of People with Disabilities (CRPD), the Convention on the Elimination of Discrimination Against Women (CEDAW) among others have been ratified by the government of Uganda to promote equality and combat discrimination.



Hon Shifrah Lukwago from Uganda Human Rights Commission making remarks on the NAP validation

In the 18th Annual Report to parliament, the Human Rights Commission recommended for the government to ensure that it exempts taxes on sun screens and for the provision of skin drugs, lotions, sun glasses free of charge to persons with albinism.

The commission is committed to amplify existing voices and active participation of persons with albinism. The existence of the NAP would go a long way in ensuring the protection and promotion of their rights is attained.

Persons with albinism were called upon to be part in the parish development model and to organize themselves in groups so that they benefit from the 10 billion disability grant given out by the Ministry of Gender Labour and Social Development.



Hon Asamo Hellen Grace- the Chief guest on the report validation meeting giving her speech.

“As we validate this action plan, we seek to have it launched as soon as possible and incorporated into National Disability action plan. I commend the UN human Rights, Open Society of East Africa, Uganda Human Rights who have supported this and I call upon all Development Partners and other stakeholders to join hands and support this noble cause geared towards inclusion of persons albinism.” said honorable.



Recommendations

- There is need to engage Uganda Bureau of Statistics (UBOS) to dissect disability (12.4%) to specify needs of different disabilities categories.
- There is need for persons with albinism to organize themselves in groups so that they can benefit from the disability grant given out by the government.
- The honorable asked the team to avail her with information to include in the report that she would soon take to the Head of state.



Conducted Annual General Meeting-one way to strengthen the capacity of Albinism Umbrella.

Holding an Annual General Meeting is one way to fulfill the constitutional requirement in which members are updated on the achievements and operations of an organization. Albinism Umbrella, delights in having this meeting annually as it strengthens her internal capacity to implement her mandate.

The meeting held on November 25 at Golf course Hotel-Kampala was the second of its kind with a major focus on filling the vacant position for the chairperson, 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 2020.



Left: Documents presented in the AGM. Right: AU Members at the event

The Board Chairperson- Mr. Moses Mukuru thanked members for their presence at such a time when the Board is supposed to account to what transpired during the year 2020 and what was achieved at the policy level. He highlighted the AU structures, led members through the policies that had been developed and approved. He noted the need to elect a new board chairperson to replace the former chairperson who had stepped down.



Left: Mr. Moses Mukuru- AU Board Chairperson makes his remarks and Right: Ms. Juliana Nantaba- Board secretary presenting the constitution at the AGM.

The Board Secretary took members through the 2020 AGM minutes and emphasized the relevance in membership subscription after which a management report was presented by the Executive Director highlighting the achievements and activities implemented in the previous year following the different strategic objectives.



Left: The Executive Director (left) and Right: Mr. Fred Bawunha (right) presenting the management report and audit report respectively.

The Audit report for the financial year 2020 was presented by the auditor with highlights on AU income and expenditure, assets, the impact of the pandemic on business at AU, and audit opinion as extracted from the report.

Election of Board Chairperson and committee member was conducted in a secret ballot exercise which saw Mr. Simon Peter Okwi and Dr. Isaac Kyazze in the pictures below emerge as the new Chairperson and member elect respectively.



In the picture above, Mr. Moses Mukuru- returning officer as elected by the AGM counting ballots for contestants.



Left: Mr. Simon Peter Okwi, the In-coming Board chairperson and Right: Dr. Isaac Kyazze, elected board member.

In his inaugural speech, the new Chairperson thanked the AGM for the trust they put in him and pledged to offer his full support and commitment. He gave thanks to the former Chairperson, Allen Bonabana in her absentia, for the time and commitment she gave during her term. He specifically appreciated Moses Mukuru, who is now his Vice Chairman for mentoring him and for his great leadership. He also applauded the “committed” Albinism Umbrella Board members and the secretariat which he said makes things happen. Dr. Isaac in the same essence also promised excellency during his term as a board member.



Participation in the commemoration of the International Day of Persons with Disabilities (IDPD)

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 promoting the rights and well-being of persons with disabilities at every level of society

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 2021 was “Not all Disabilities are Visible”.

As one of the pre-cursor activities, the MGLSD together with partners held a national symposium on disability inclusion under the theme, “All disabilities matter, a call for inclusion Action”. The event aimed at raising awareness on categories of invisible disabilities and their development agenda. This symposium ushered into the national celebrations that were held at the State house presided over by His excellence the president of Uganda.



Photo moment of the delegates with H.E the President of the Republic of Uganda at State house- Entebbe during the IDPD commemoration- December 3rd, 2021

Celebrations took place in State House in Entebbe with H.E the President of the Republic of Uganda Yoweri Kaguta Museveni as the chief guest. Other delegates were from different ministries, parliament (members representing persons with disabilities), National Council for persons with disabilities, the Equal Opportunities Commission, organizations of persons with disabilities, development partners among others. Albinism Umbrella was privileged to be represented by its Executive Director, Ms. Olive Namutebi.

Key highlights of the day

In her remarks, Hon Hellen Grace Asamo who represented the members of parliament with disabilities highlighted a number of issues affecting the disability fraternity. She made a request to the president for the provision of heifers, goats, piglets, increment of special grants from 9.6 billion shillings to 16.15 billion shillings and to meet leaders of persons with disabilities in Kyangwali to listen to their challenges.

While delivering his speech, the president accepted the increment of the special grant and provision of NAADs products for the purpose of addressing the household livelihood of persons with disabilities. However, he requested the state minister to specify whether PWDs want heifers or goats. Also granted was the request to meet leaders of persons with disabilities especially the five members of Electoral College for two weeks in Kyangwali (NALI) for cadre training.



Celebration of the International Albinism Awareness Day- June 13th.

On 18 December 2014, the General Assembly adopted a resolution proclaiming, with effect from 2015, 13 June as International Albinism Awareness Day in an effort to stop the brutalities against people with albinism. In response to the call from civil society organizations advocating to consider persons with albinism as a specific group with particular needs that require special attention, on 26 March 2015, the Council created the mandate of Independent Expert on the enjoyment of human rights by persons with albinism.

Strength Beyond All Odds was the international theme for 2021 which was chosen to highlight the good qualities of persons with albinism around the world and show that they were made to defy all odds. It is also meant to celebrate how people with albinism worldwide meet and exceed expectation in all domains of life.

The emergency of Covid 19 with restrictions on public gatherings made Albinism Umbrella and its supporting partners, the UN Human Rights Office in Uganda and the Ministry of Gender, Labor and Social Development postpone from its annual celebration of June 13 to December 18, 2021 at Kabarole district grounds. Participants included representatives of the Ministry of Health, Ministry of Gender, Labour and Social Development, OHCHR, Kabarole District Local government, Albinism Umbrella, CBOs of persons with albinism media, parents, guardians of and persons with albinism from different districts.

The main objective of IAAD is to create awareness and advocate for inclusion of persons with albinism in development programs.

Key highlights of the day

Ms. Olive Namutebi highlighted some of the milestones registered by the albinism fraternity despite the great effects the pandemic. These included; passing of the 2020 persons with albinism Act, moving of the National Action Plan on Albinism to the MGLSD, accomplishment of spatial mapping for 35 districts across the country, distribution of sunscreen to every family with persons with albinism and presence of a new UN independent Expert among others.



She also noted that that persons with albinism lack sufficient knowledge on sexual reproductive health and rights, thus the ministry of health was tasked to provide trainings to health workers to extend SRHR information to persons with albinism and to adequately counsel and support mothers giving birth to children with albinism.

Also highlighted was the need to engage local leadership in the protection of the rights of persons with albinism since local leaders are considered as credible change agents, allies and influencers in the community. *Olive in an orange Jacket (above)* appealed to the Ministry of Health to support sunscreen production in Uganda given that it is a vital ingredient to the lives of persons with albinism.



Ms. Florence Epodoi-
Program Officer UN Human
Rights giving her remarks on
the day

Ms. Epodoi Florence (UN Human Rights) emphasized the principles of universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms and the need for persons with albinism to be guaranteed the full enjoyment of their rights and freedoms without discrimination. She called upon parent's/care takers to teach young ones about equality and non-discrimination and advised them to be advocates and ambassadors for the rights of persons with albinism in whichever spaces they may find themselves.



Ms. Agnes Nampeera Bulega

Ms. Agnes Nampeera Bulega, the permanent secretary at the MGLSD in the picture below noted that the government has put up different programs to improve the status of persons with disabilities for instance the special grant at MGLSD. She advised persons with albinism to organize themselves into groups such that they benefit from the program and many more like Youth Livelihood Program and Uganda Women Empowerment Program.

In her speech, Ms. Nampeera gave an assurance to the audience that the MGLSD shall pass the National Action Plan on Albinism for it is an important tool in addressing the issues of persons with albinism.

She called upon the ministry of health to join hands with the MDLSD to ensure that they continue serving persons with albinism especially in the areas of sunscreens, issues of sexual reproductive health, reasonable accommodation for learners with albinism, and awareness.

Sharing of success stories

In relation to the year's theme of Strength Beyond All Odds, Albinism Umbrella identified rightsholders to share their experiences to inspire their peers and to change community perceptions towards persons with albinism.



Loyce Peninnah Kituyi sharing her
experience.

Peninnah is a fresh graduate of Makerere University with a first-class degree in Arts with Education majoring in Literature and English. She believes that self-valuation, realization and determination made her defy all odds and made it to the top throughout her academic journey. Intelligent she is, Peninnah won herself scholarships right from primary up to the university where she was admitted on government sponsorship. Apparently, she is an aspiring student of Oxford

and strives to become an assistant Professor in Linguistics. "You need to calculate your time well if you want to succeed" mentioned Kituyi.

Peninah testified that she was stormed and shaken by negativity, stigma, hate but this did not put her down since she had parental support. Visual impairment was also a challenge given that she was reading hard and she almost lost her sight. She therefore called upon parents to show the first

love to their children with albinism before anyone else in the community and encouraged learners who can afford eye glasses to use them before losing their sight.

Due to her passion about albinism, Peninnah intends to use her profession as a teacher to create awareness about albinism given that she will be meeting with people from all walks of life and of different backgrounds.

She advised learners to read hard, keep in school and believe in themselves that they can all make it despite their disability. Also appreciated was albinism Umbrella for granting her a platform to share her story and show her peers that everything is possible once one is determined.



Lydia is also a fresh graduate with Bachelor’s degree in social work and social administrative from Makerere University. She is the district counsellor representing persons with disabilities and a state minister of gender in Butalejja district. “To my fellow persons with albinism, you need to have self-esteem and self-determination so that the community can value you.” emphasized Lydia.



Dr. Richard Mugahi addressing the participants at IAAD.

The celebration was graced by Dr. Richard Mugahi - Assistant Commissioner Reproductive and Infant Health, who represented the Minister for Primary Health Care and the Area member of Parliament. He said that Albinism is one of the invisible disabilities due to its complex nature, stigma and discrimination associated with it. The health challenges faced by persons with albinism cannot let them work for long hours under the sun as it causes skin cancer, their sight cannot let them read clearly hence he called for a need for protective gears.

albinism, Dr. Mugahi said that the plan is a positive move to provide monitoring steps towards the enjoyment of human rights for persons with albinism. He committed to organize a meeting between leaders of persons with albinism and the Minister of Health so that they present their issues on sunscreens and eye care.

He also observed that there is need to issue a guideline to health facilities for persons with albinism to be given priority when accessing health services and emphasized Article 7(7) in the persons with disabilities Act 2020 which stipulates that government shall provide persons with albinism with skin protective creams and persons with disabilities with assistive devices at no cost or subsidized prices

The commemoration was concluded with Covid-19 immunization in a bid to reduce the risk of contracting the virus by the community. Over 25 doses of Johnson and Johnson were obtained from Fort Portal main hospital and 20 people got immunized after a thorough sensitization about its relevance by the Commissioner.

On the validated National Action Plan on



Participants lining up to take the Covid 19 jab (left) and Ms. Olive Namutebi receiving the injection on the right.



Partnership with Civil Society Organizations.

Albinism Umbrella sought to establish partnership with Civil Society Organizations to jointly advance the diverse needs of Persons with albinism.

Christian Blind Mission (CBM)



Phillip Makasi having sight challenge while reading.

It should be noted that a significant percentage of persons with albinism have a visual challenge caused by lack of melanin in the development of the retina. This can be addressed by conducting eye checkups and introducing protective gears like sun glasses, binoculars, spectacles to adjust and adapt to their day-to-day activities. However, there is not many persons with albinism that can afford such services to enhance eye care.

We deliberately sought for partnership with CBM, a Christian International Development Organization, committed to improving the quality of life of people with disabilities through its programmes like Inclusive Eye Health, Community Based Inclusive Development, Disability Inclusive Development among others.

Albinism Umbrella has since had its partnership approved after a number of productive engagements and undergoing through partnership assessment. So far, some AU staff have received training on safeguarding and more collaboration is anticipated between the two organisations.

Fida Uganda

Albinism Umbrella signed a Memorandum of Understanding with FIDA Uganda upon establishing a partnership that will aim at enhancing access to justice for women with albinism as well as promoting gender equality and women's human rights.

As a result, FIDA is collaborating with Albinism Umbrella to implement a 3 years' project with the objective of enhancing access to justice for women with albinism. In this project, FIDA will provide



Albinism Umbrella in partnership meeting with a member from FIDA UGANDA.

free legal aid services including legal advice, legal representation, counseling and legal education to women with albinism.



Ms. Olive Namutebi highlighting about the plight of albinism during FIDA AGM-2021.

We have also attained various platforms to create awareness about albinism. For example, at FIDA Uganda's 2021 Annual General Meeting, Executive Director-Albinism Umbrella was invited as a key note speaker to highlight the plight of persons with albinism in Uganda and to create awareness about the condition. Similarly, Phiona Nantaba Administrative Assistant at Albinism Umbrella was engaged in a discussion about addressing Gender Based Violence among persons with albinism during the commemoration of 16 days of Activism against gender-based violence.

Membership with National Union of Persons with Disabilities (NUDIPU)

Albinism Umbrella believes in collective advocacy to achieve an amplified voice for inclusion of persons with albinism. This prompted her to enter in to partnership with NUDIPU, an umbrella organization that advocates for the inclusion of Persons with Disabilities and their concerns in the mainstream development processes. These partnerships equip organizations with information and knowledge about concerns of persons with albinism that they can prioritize in their advocacy agenda



Conducted trainings in Convention on the Rights of Persons with Disabilities, Sustainable Development Goals and advocacy

As part of strengthening the capacity of its Board, staff and regional structures, Albinism Umbrella conducted trainings on the Convention on the Rights of Persons with Disabilities, Sustainable Development Goals and advocacy. The objective was to build their understanding on the concepts and to improve their advocacy skills to effectively negotiate with government and other policy implementers regarding inclusion of persons with albinism in mainstream development processes. This was made possible by Disability Rights Fund.



Distribution of in-kind donations.



Albinism Umbrella branded masks donated by X-ERA branding

Throughout the year, Albinism Umbrella receives in-kind donations to support persons with albinism acquire basic necessities of life. Among those received in 2021 included sunscreen lotions, food stuffs, clothing, face masks, beddings and sun glasses among others.



A child with albinism in Wakiso receiving sunscreen from AU staff with support from UN Human Rights.

A number of partners, well-wishers and individuals have come out to support this cause with what seem to be little but makes a tremendous difference in the lives of persons with albinism. This year 2021, African Albinism Foundation; UN Human Rights; Strive for Jana; Duvet Lady, Aga Khan Foundation, X-Era and other individuals are among the partners who supported this cause. Over 70 rightsholders from different parts of the country have benefited from these donations.

Below is pictorial for distribution of in-kind donations to persons with albinism



Admin assistant handing over duvet donation to beneficiary



Group photo with the team from Strive for Jannah and some of our beneficiaries.



Food donations received for persons with albinism during lockdown



Albinism Umbrella receiving clothes donation from Aga Khan Foundation officer



More donations for persons with albinism



Media activities.

In order to harness the power of media as a mode of communication, Albinism Umbrella has used several platforms in creating awareness about issues affecting persons with albinism and influencing the society to defend and promote rights of people with albinism. Several media platforms including; radios, televisions, social media, YouTube, LinkedIn have been used to amplify messages on albinism. Albinism Umbrella conducted a number of Radio and television talk shows about cares and needs of people with albinism with the main aim of opening up spaces for persons with albinism to participate in the economic development and wellbeing of their communities.

These channels have also allowed the organization to massively close the gap on the knowledge concerning albinism and its causes, demystify preconceived perceptions about albinism, fight stigma and discrimination and advocated for upholding of rights of persons with albinism. This has created awareness and we have since seen persons with albinism take on leadership positions as a result of the media campaigns. This year, our regional structure leaders took the mantle of raising awareness in the different regions and this has greatly built their capacity to engage with duty bearers and community members.



Barbra Anyinge- PWA leader and Olive Namutebi creating awareness about albinism on Voice of Lango in Lira district- Northern region.

Through talk shows on stations like 88.0 Voice of Lango (North), Jubilee radio, TV West-(West), Albinism Umbrella was able to share findings of the spatial mapping research and news bulletins on NTV were made to create awareness about albinism and our programs.



In the picture (right), Ms. Namutebi Olive engaged in a talk show on NTV about the performance of the National special grant for persons with disabilities. This was in collaboration with NUDIPU and the MGLSD.

Conclusion

People 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 people with albinism; stigma and discrimination, barriers to access to justice, poor access to social services. The organization is calling 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 people with albinism enjoy all rights and freedoms enjoyed by all.

OUR STAFF



Olive Namutebi
Executive Director



Henry Mujuni
Finance and
Administration Officer



Nicole Phiona Nantaba
Administration Assistant



Janepher Nanyondo
Program Officer



Ivan Kagudde
Administration volunteer



Doreen Nakuti
Monitoring and Evaluation
Officer

BOARD OF DIRECTORS



Simon Peter Okwi
Chairperson



Moses Mukuru
Vice Chairperson



Brenda Bonabana
Treasurer



Juliana Nantaba
Secretary



Isaac Kyaze
Member



Isabella Akiteng
Akiteng



Barbara Anyinge
Member



PARTNERS

We work with partners to build a society in which persons with albinism are dignified and included in all development processes.

- Luwero District Albinos' Association
- Albinism Association for Development
- Albino Organization for Bundibugyo and Ntoroko Districts.

Donors

- Disability Rights Fund-DRF
- GIZ- Civil Society in Uganda Support Programme
- VOICE- Oxfam Novib

Government institutions

- The Equal Opportunities Commission
- The Parliament of Uganda
- Ministry of Gender Labor and Social Development

Health Institutions

- Mengo Hospital

Human Rights agencies

- Office of the United Nations High Commissioner for Human Rights (OHCHR).

Civil Society Organizations.

- National Union of Disabled Persons of Uganda- NUDIPIU.
- BareFoot Law-BFL
- FIDA Uganda
- Uganda Women's Network-UWONET

2021 IN PICTURES



AU Board, members and staff posing for a photo during the Annual General Meeting



Participants at the report validation of the spatial mapping research conducted in Central, Western and Northern Uganda.



Participants at the report validation of the spatial mapping research conducted in Central, Western and Northern Uganda.



The permanent secretary- MGLSD, the Assistant Commissioner for Reproductive Health-MOH and Executive Director- Albinism Umbrella at IAAD in Fort Portal.

FINANCIAL REPORTS


ALBINISM UMBRELLA ANNUAL REPORT AND AUDITED FINANCIAL STATEMENTS AS AT 31 DECEMBER 2021

STATEMENT OF FINANCIAL POSITION

Particulars	Note	31-December-2021 Ushs	31-December-2020 Ushs
ASSETS			
Non-Current Assets			
Property and equipment	2.7	387,500	982,000
Current Assets			
Cash and Cash Equivalents	2.8	157,345,794	99,287,333
Advances		1,330,000	-
		158,675,794	99,287,333
TOTAL ASSETS		159,063,294	100,269,333
RESERVES & LIABILITIES			
Reserves			
Accumulated Fund		145,756,134	87,434,333
Current Liabilities			
Trade and other payables	2.9	13,307,160	12,835,000
TOTAL RESERVES AND LIABILITIES		159,063,294	100,269,333

The financial statements were approved by the Board of Directors on 25th / 03 /2022 and were signed on its behalf by:

CHAIRPERSON



TREASURER



ALBINISM UMBRELLA ANNUAL REPORT AND AUDITED FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2021

STATEMENT OF INCOME AND EXPENDITURE

Particulars	Note	31-December-2021 Ushs	31-December-2020 Ushs
Income			
Grants income	2.1	500,544,827	221,512,000
Other income	2.2	9,696,100	2,082,005
TOTAL		510,240,927	223,594,005
Expenditure			
Staff costs	2.3	128,263,160	58,756,960
Administration costs	2.4	44,800,181	26,753,946
Program Expenses	2.5	276,210,949	91,437,707
Finance Costs	2.6	2,050,336	1,328,992
Depreciation	2.7	594,500	1,211,750
TOTAL		451,919,126	179,489,355
SURPLUS FOR THE YEAR		58,321,801	44,104,650



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