



ANNUAL REPORT 2023

Our collective efforts in nurturing Persons with Albinism



LIST OF ACRONYMS

AGM	Annual General Meeting
AU	Albinism Umbrella
BOD	Board of Directors
CBM	Christian Blind Mission
CSC	Community Score Card
CSOs	Civil Society Organisations
CRPD	Convention on the Rights of Persons with Disabilities
DCDO	District Community Development Officer
FGD	Focus Group Discussion
FIDA-U	The Uganda Association of Women Lawyers
IAAD	International Albinism Awareness Day
IDPD	International Day of Persons with Disabilities
IEC	Information Education and Communication
MoGLSD	Ministry of Gender Labor and Social Development
MOH	Ministry of Health
NAP	National Action Plan on Albinism
NCD	National Council for Persons with Disabilities
NUDIPU	National Union of Disabled Persons of Uganda
OURS	Organized Useful Rehabilitation Services.
RMH	Ruharo Mission Hospital
SASA	Self Awareness-Self Acceptance/Advocacy
SDGs	Sustainable Development Goals
SIELEH	Sustainable Inclusive Economic Livelihood and Eye Health
UGANET	Uganda Network
VAWG	Violence Against Women and Girls

EXECUTIVE SUMMARY

This report provides a comprehensive account of the initiatives undertaken by Albinism Umbrella throughout the year 2023, to strive towards our vision and maintain our core values. It also reflects our commitment to improving the quality of life of persons with albinism, serving our community and to enhance the working life of our employees.

In 2023, Albinism Umbrella improved the quality of life of persons with disabilities through extending a series of health care services to persons with disabilities. Among these include eye care services, distribution of assistive devices, assessment of children with therapeutic and rehabilitation, and facilitating access to specialized services. This was done in collaboration with partners like Ruharo Mission Hospital (RMH) and Mengo Hospital.

Recognizing the crucial link between economic empowerment and overall well-being, Albinism Umbrella prioritized initiatives aimed at fostering financial inclusion and independence among persons with disabilities, including persons with albinism. We mobilized and formed 72 ISAVE groups, built their capacity in different aspects of life, created linkages with government programs, provided business skills training and startup kits, among others. This helped in breaking down societal barriers and fostering entrepreneurship within the albinism community.

In the facet of research and advocacy, we utilized our evidence based data from the spatial mapping research, developed and published a position paper on albinism.

The focus was to raise awareness in regards to the persistent challenges faced by persons with albinism, including discrimination, marginalization, and limited access to resources and opportunities. We also sought to influence decision-making processes, and mobilize support for advancing collective efforts towards addressing pressing challenges facing the albinism community.

Community engagement remains central to the organization's mission, with a range of outreach activities impacting thousands of individuals through school programs, community dialogues, radio talk shows, and health outreaches. In 2023, collaborative efforts with healthcare institutions like Mengo Hospital were embraced and we were able to extend awareness and essential services to schools, impacting a number of people within school communities.

In 2023, Albinism Umbrella was supported by a number of donors and partners in the execution of its mandate including; Disability Rights Fund, Christian Blind Mission, Aga Khan Foundation KF, VOICE, The Constellation, Germany Cooperation, Ruharo Mission Hospital, Mengo Hospital and the Government of Uganda.

FOREWORD BY THE CHAIRPERSON



We are happy to have climaxed our interventions under our first ever strategic plan (2018-2023). We stand tall and proud to say we have laid a firm foundation for Albinism Umbrella in realizing our vision in creating a society in which Persons with Albinism are dignified and realize their full potential.

In the last five years, we have laid a strong footprint for the organisation to mobilise, engage and uplift the lives of persons with albinism.

2023 has been an opportunity to continue striving to promote and protect the rights of persons with albinism in Uganda through research, partnerships and advocacy for their improved wellbeing. This year also marks the end of our board tenure and we are proud to have made our contribution in enabling Albinism Umbrella grow as a strong rightsholders led organisation.

In terms of financial performance, we have seen an interest by development partners. In 2023, we gained new funding from VOICE, Disability Rights Fund, Christian Blind Mission and our funding has grown from Ugx 656,879,643 to Ugx 738,193,600. We must observe that as a board, we are proud of this achievement and pledge to continue providing the leadership required to keep up with the work ahead of us.

Moving forward, we are excited to reflect on our progress, limitations as we plan to embark on the journey of our new strategic plan (2024-2028) which will pave way for scaling our work.

We look forward to working harmoniously with our members partners in Uganda and abroad.

A handwritten signature in black ink, appearing to read 'SP Okwi'.

Simon-Peter-Okwi
Board Chairperson

FOREWORD BY THE EXECUTIVE DIRECTOR



I am immensely proud to present this report detailing our organization's endeavors and achievements in advancing the rights and well-being of Persons with Albinism. Our vision of "A society in which persons with albinism are dignified and realize their full potential" drives every aspect of our mission, from research and advocacy to partnership and community engagement.

The year 2023 marked the end of our 5-year strategic plan, which was a trying one I should note, but we persevered through the challenges and came through with several milestones. This was a period largely, of pioneering new ways of working, putting together structures, strategically positioning Albinism Umbrella,

generating data on the actual status of persons with albinism in the country as a benchmark for evidence based programming, and raising awareness in respect to the human rights and social justice within the albinism community.

Health remains a major bottleneck to the full enjoyment of life by persons with albinism.

The rising cases of deaths caused by skin cancer amidst the sunscreen scarcity, coupled with absence of a long lasting solution is a matter that calls for immediate attention. In 2023, we embarked on a feasibility study, assessing the viability of establishing a sunscreen manufacturing facility. This exemplifies our commitment to addressing the unique needs of rights holders, ensuring access to essential products while exploring avenues for economic empowerment.

Through strategic partnerships with institutions like Ruharo Mission Hospital (RMH) and Mengo Hospital, we provided free eye care services, mitigating the risk of vision deterioration and promoting overall health among persons with disabilities. Additionally, our SIELEH project, in collaboration with OURs-Ruharo, delivered rehabilitation services to children with disabilities, promoting their right to health.

Raising awareness about albinism lies at the heart of our mission thus we developed and disseminated the Albinism health handbook to educate communities about albinism and to promote inclusive healthcare practices. In a bid to promote economic inclusion,

we carried out business skills training, provided startup kits, and mentored persons with albinism on job readiness to promote financial independence and dignity.

We recognize the importance of advocacy in effecting systemic change. Albinism Umbrella developed and published a position paper leveraging spatial mapping research to raise awareness of the challenges faced by persons with albinism and to mobilize support for meaningful interventions. We also conducted a series of community information sessions, reaching thousands of people through various platforms, thereby fostering understanding and acceptance of albinism.

As we reflect on our accomplishments in 2023, we are inspired to continue our journey towards a more inclusive society where every person, regardless of disability, can actively participate and contribute to social and economic progress.

I extend my heartfelt gratitude to our partners, stakeholders, Board of Directors and dedicated team members for their solid support in realizing our vision. Together, let us continue to champion the rights and well-being of persons with albinism, striving for a future where dignity, inclusion, and opportunity are accessible to all.

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

Olive Namutebi

Executive Director, Albinism Umbrella

MESSAGE FROM A PERSON WITH ALBINISM



Agnes Kabogere

I was overjoyed when Albinism Umbrella arranged to visit my home. My neighbors began to appreciate me, seeking my company because I had connected with an organization that genuinely cares for me. Now, I appreciate life, moving about confidently without enduring hurtful insults. In the past, such words would bring tears to my eyes, but today, I am content and grateful for the goodness life brings!

Before I connected with Albinism Umbrella, my skin was parched and cracked. I bore wounds, and my lips were chapped, often accompanied by white discharges in my eyes, impairing my vision. However, since meeting Albinism Umbrella, they have provided me with wide-brimmed hats and eyeglasses.

What I had overlooked thanking them for, is their provision of sunscreen. Remarkably, my skin has transformed it no longer cracks, and its appearance has significantly improved. People now inquire about my skincare secret, and I credit it all to the sunscreen. I sincerely hope that Albinism Umbrella continues to supply us with sunscreen.

ABOUT ALBINISM UMBRELLA

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. For details about our vision, mission, objectives and overall story, visit our website - <https://albinismumbrella.org/>.



Our Results At a Glance



Developed
business plan
for local sunscreen
Production



500
received assistive
devices and materials



906
reached with
eye-care
services



172
Children assessed
and provided with
multidisciplinary
services



Albinism Health
Handbook
disseminated



2,149 mobilized for
ISAVE saving groups
44 linked to financial
services
9 groups linked to
government programs



29 received
start-up
kits **18**
empowered
to integrate
into the
workforce



Position paper
on albinism
disseminated



4,705,190
reached during
awareness
sessions



21 schools reached
with awareness, skin
and eye care services



4.5m
reached
through
television and
radio programs



Commemorated
the International
Albinism
Awareness Day



Successfully held
**Annual General
Meeting (AGM)**



**Supported
trainings** for Persons
with Disabilities and
staffs



Participated in
Local and regional
learning and sharing
events

WHAT WE ACHIEVED IN 2023

HEALTH

Strategic Objective: Increasing the life expectancy and quality of life through access to quality health services accorded to persons with albinism

Persons with albinism are majorly affected by societal neglect and health. In respect to health, the skin and eyes pose the greatest hindrance to living a dignified life. They are all categorized as legally blind as the involuntary eye movement cannot be corrected for a better vision. Research shows that 80% of persons with albinism succumb to skin cancer when exposed to the harmful Ultra Violet rays from the sun. By prioritizing this objective, Albinism Umbrella aims to mitigate these unique health challenges, thereby fostering better health outcomes and improving their overall well-being.

necessary infrastructure and technology requirements, estimating the initial investment and operating costs, evaluating the regulatory and legal considerations, and conducting a financial analysis. This provided useful insights, including recommendations to start a local sun screen production facility. As a result, a five (5) year business plan for the "Sunshield Limited", a proposed social enterprise was developed as a sustainability strategy for Albinism Umbrella.

We conducted a feasibility study for local sunscreen production

Albinism Umbrella commissioned a study in four (4) districts of Kamuli, Wakiso, Kampala and Kyegegwa to address the challenge of limited access to sunscreen due to supply chain limitations. The assessment conducted by Capital Solutions Ltd, involved determining the viability of establishing a sunscreen manufacturing facility, not limited to; evaluation of the market demand for sunscreens, assessing the availability and cost of raw materials, analyzing the



Interview with a mother with a child with albinism

Distribution of assistive devices

Albinism Umbrella distributed assistive devices such as reading glasses, wide-brimmed hats, and sunscreens among persons with albinism geared towards improving their quality of lives and fostering greater inclusivity of beneficiaries in day-to-day activities within their communities.



Sunscreen distribution to beneficiaries after a project launch in Kamwenge District. In presence was the CBM Italy CEO-Mr. Massimo Maggio on the extreme right.

Sunscreen



Wide Brimmed Huts



Sun/Reading glasses



Distributed:

5700

bottles

300

pieces

300

pairs

Reached:

435

(273F, 162M)

300

(177F, 129M)

300

(143F, 125M)

Community Health outreaches

Eye camps/Eye care clinics

Through collaboration with specialized partners like Ruharo Mission Hospital and Mengo Hospital, Albinism Umbrella organized free eye care services to identify and address potential complications promptly, thus mitigating the risk of further vision deterioration. The intervention also served to avert vision impairments, such as photophobia, nystagmus, and refractive errors. Regular eye screening and check-ups are crucial for early detection and management of these issues, through tailored treatments and assistive devices, such as prescription, eyeglasses and tinted lenses, which can lessen symptoms and improve visual function.



An ophthalmologist performing an eye check up on a child with albinism.

Number conducted

5

**Beneficiaries reached:
(596F,310M)**

906



Persons with albinism acquiring different eye care services during one of the health outreaches in Masaka District

Assessment/Identification of Children (0-10 years) with therapeutic and rehabilitation needs

In the year 2023, Albinism Umbrella, through its SIELEH project worked in partnership with OURs- Ruharo, to assess children with disabilities and ensure those with therapeutic and rehabilitation needs receive comprehensive services. OURs also extended disability capacity sessions to parents/care givers, provided treatment, made referrals and recommendations for further assistance. Children's right to health was guaranteed through services that relieved pain, restored hope to those who accessed surgeries, treatment and rehabilitation.



Mr. Arron Ndyowaawe, a Pediatric occupational therapist from OURs-Ruharo educating and training a caregiver, during children assessment at Rukunyu District Hospital in Kamwenge District.

172

(78F,94M) children identified and provided with multidisciplinary services

25

Mothers provided with Folic acid tablets 4500

11

(4F,7M) children supplied with silverfish



A team from Ruharo Hospital examining a child with albinism during an outreach at Kyegegwa General hospital in Kyegegwa district.

Development and dissemination of an Albinism Health Handbook

Albinism Umbrella developed an Albinism Health Handbook with the aim to raise awareness about albinism. The book was developed with support from experienced stakeholders including; representatives from the Ministry of Health, Mengo Hospital - Low Vision department, persons with albinism and care takers of children with albinism. The book contains prevailing health challenges facing the community, tips on how these can be addressed plus the frequently asked questions. 200 copies were printed and distributed to different stakeholders.



A picture of Stakeholders during the drafting of the Albinism Health handbook

ECONOMIC EMPOWERMENT

Strategic Objective: Improving livelihoods, the Economic wellbeing and meaningful financial inclusion of persons with albinism

Economic empowerment enhances the overall well-being and quality of life for persons with albinism. Persons with albinism often face significant barriers to economic participation and financial inclusion stemming from societal discrimination, limited access to education and employment opportunities, and inadequate support systems <http://bit.ly/ws/GdAY>. By prioritizing economic well-being and meaningful financial inclusion, Albinism

Umbrella underscores its commitment to fostering independence, dignity, and self-sufficiency among persons with albinism, while also setting a precedent for broader disability inclusion initiatives.

During 2023, we registered the following milestones;

Formation of ISAVE groups

ISAVE is an inclusive programme, adapted from NUDIPU, designed to remove barriers that hinder the financial inclusion and participation of persons with disabilities. The 30-member group is comprised of persons with disabilities, Care givers and other community members/well-wishers.



Programs Officer-Ms. Janepher Nanyondo meeting some of the ISAVE group members during one of the project monitoring visits in Kamwenge district

ISAVE groups formed:

72

Groups registered:

72

Members mobilized:

2149

Linked to financial services:

44

Illustration of members mobilized

District	Total	F	M
Kyegegwa	823	510	313
Kamwenge	1326	921	405
Over all total	2149	1431	718

ISAVE Kits distributed: 72

Through the Sustainable Inclusive Economic Livelihood and Eye Health (SIELEH) project, Albinism Umbrella has built ISAVE members' capacity in financial literacy and saving, resulting in creation of self-managed and self-capitalized savings from which flexible loans can be accessed by members. Social cohesion between and amongst participants has been enhanced, thus facilitating the inclusion that Albinism Umbrella aspires to attain.



Programs Officer handing over ISAVE kits to the Project Officer at AU District Office in Kamwenge

Linkages of groups to government programs

Albinism Umbrella has enhanced the socio-economic inclusion of persons with disabilities, including those with albinism through linking them to government programmes. Through the office of the Residential District Commissioner, Kamwenge district, AU linked 5 (2F, 3M) persons with disabilities aged 14-20 years to the "Presidential Initiative for Skilling the Youth" program that took place in Kyenjojo district. All the five, selected from the formed ISAVE groups in Kamwenge acquired skills in different fields not limited

to, hair dressing, welding, tailoring, among others. With support from CBM, Albinism Umbrella will provide start up kits for these youths to boost their income levels. The impact of this initiative extends beyond immediate access to government programs, empowering persons with disabilities to advocate for their rights, challenge societal barriers, and achieve meaningful socio-economic empowerment.

Number of groups linked:

9

Number that received the grant:

3

In progress:

6

Trainings

Business coaching and management



The trainer, Mrs. Hanah Owot taking participants through the dynamics of business at Albinism Umbrella offices in Kanyanya.

In 2023, Albinism Umbrella trained 56(43F, 13M) rightsholders in business skills and management to equip them to start, manage and sustain their businesses. By the end of the training, participants received support in business idea generation and on best business practices.

Provision of startup kits to promising small scale businesses

29 (19F,10M) rightsholders, including persons with albinism and their care takers, with business plans were given monetary kits as a way of promoting financial independence and fostering a sense of dignity and inclusion within the society.

Mentorship on job readiness and preparedness

Albinism Umbrella extended a training on job readiness and employability to 18(11F, 7M) persons with albinism on job search strategies, resume writing, professional etiquette, adaptability and flexibility, self-confidence building, among others. The intervention will serve to avert the unique

challenges in accessing employment opportunities due to the misconceptions and discrimination associated with their skin leading to wide un/ under employment and ultimately high poverty levels.



Mr. Martin Lubwama, the facilitator emphasizing a point during the session, at Albinism Umbrella Offices in Kampala.

RESEARCH AND ADVOCACY

Strategic Objective: To advocate and engender programmes and interventions that are evidence based, to ensure tailor-made responses for persons with albinism

The bedrock of Albinism Umbrella work is based on data and evidence. Throughout the last 5 years of our strategic plan (2019-2023) our evidence generation interventions have allowed us know the albinism prevalence in the nation, nature and extent the problems they face, conditions under which they live, societal attitudes, extent of inclusion and/or exclusion. This evidence has enabled us have tailored programmes that have responded to their needs.

Research dissemination through publications; Position paper on albinism

Using findings from the spatial mapping research conducted in 2021, Albinism Umbrella developed and published a position paper (Page 3, February 22, 2023, in New Vision gazette), leveraging evidence-based insights to raise awareness in regards to the pervasive challenges faced by persons with albinism, including discrimination, marginalization, and limited access to resources and opportunities. It was also intended to influence decision-making processes, and mobilize support for advancing collective efforts towards addressing pressing challenges facing the albinism community, through recommendations.

The pipeline will be buried 1.8m to 2m underground. This will be deeper where it crosses rivers and lakes

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Commemoration of the International Albinism Awareness Day-June 13

Albinism Umbrella provided leadership in the International Albinism Awareness Day 2023, celebrated in Masaka City under the global theme **"Inclusion is Strength,"**. The event which attracted 224 (115F,109M) participants marked a significant milestone in advancing the rights and visibility of persons with albinism, combat violence and discrimination, and foster community support.

Event Highlights



A peaceful march on the streets of Masaka City



Distribution of events fliers in Masaka town



Health Camp where integrated services were rendered to persons with albinism and the wider community



Albinism Umbrella's Executive Director giving remarks at the event



Ms. Patience delivering a speech on CBM's behalf at the event.



A representative from MoGLSD making remarks during the commemoration.



Ms. Esther Kyoziira, CEO-NUDIPU making remarks at the event

The event which was graced by persons with albinism, government representatives from the Ministry of Gender Labour and Social Development, Masaka City, District leaders, development partners and CSO representatives including; Executive Director of Albinism Umbrella, CBM, NUDIPU, ADD International and community leaders., , underscored the importance of unified advocacy, empowerment, and dialogue in addressing the social barriers that perpetuate marginalization and stigma against persons with albinism. There was a call for government to render healthcare, undertake education policy reform, and inclusion in empowerment programs.

The event also emphasized the urgent need for societal mindset shifts, policy implementation, and collective action to ensure the dignity, respect, and equal opportunities for persons with albinism.

Remarks by the **Chief guest, Hon. Florence Namayanja**, Mayor Masaka City highlighted;



- A discontentment about the delayed release of parliamentary fundraising

walks fund towards the establishment of a rehabilitation Centre for persons with albinism, she pledged to engage Members of Parliament to front this matter on the floor of parliament and called upon the media to drum it loud for the good of the fraternity.

- Ministry of Health freely avail sunscreens to persons with albinism in the fight against skin cancer.

She called upon Masaka city administration to disaggregate data in reports of beneficiaries of government livelihood programs for disability to allow for easier analysis and follow-up.

The International Day of Persons with Disabilities (IDPD)

Every year, Albinism Umbrella joins the rest of the disability fraternity and the world, to commemorate the IDPD, to promote an understanding of disability issues and mobilize support for the dignity, rights and well-being of persons with disabilities. It should be noted that albinism is recognized as a form of disability in the 2020 Disability Act.

Reflecting on the year's theme "**The role of Innovations in Disability Inclusion**", Hon. Betty Amongi - Minister of Gender, Labor and Social Development, emphasized government support for innovations like Kyambogo University's Omni-reader software. She also made an assurance that the National Council for Persons with Disabilities will not be merged with other Government entities as rumored. Other key stakeholders emphasized the critical need

for disability inclusion across all sectors. NUDIPU and the National Council of Persons with Disabilities highlighted successes such as online access to special grants, but also raised concerns including limited accessibility to Emyooga grants and the shelved inclusive education policy.

Government officials, including Ministers and Members of Parliament, advocated for stronger implementation of existing laws mandating accessibility and urged for continued support for persons with disabilities, stressing the importance of economic empowerment and education for this marginalized group. Recommendations included the integration of disability considerations into all government innovations, making technology both accessible and affordable, and allowing persons with disabilities to access development funds.

Commemoration of the 16 Days of activism against Gender-Based Violence

This is a global campaign that unites people and organizations in eliminating violence against women and girls. The year's theme was, "UNITE! Invest to Prevent Violence Against Women and Girls," highlighting the crucial role of resource allocation in preventing violence at its root. Despite legal

measures, violence against women and girls (VAWG) remains a prevalent human rights violation. Women and girls with albinism face additional layers of discrimination due to both gender and harmful cultural beliefs. Raising awareness of these challenges and dispelling myths surrounding albinism is therefore essential.

Recognizing the need for empowerment and representation, FIDA-U, under the UN Women and the DIGI project in partnership with Albinism Umbrella and UGANET, hosted a fun day specifically for women and girls with albinism. This event, **themed "Colors of Strength, Embracing Diversity in Action: Empowering Women with Albinism to Break Societal Barriers and Stereotypes"**, sought to promote inclusivity, celebrate diversity, and raise awareness about the challenges faced by women and girls with albinism, by creating a safe and empowering space for them to converge, share stories, and engage in wellness and creative activities. The event empowered women and girls with albinism, fostering inclusivity, breaking societal stereotypes, and raising awareness about their challenges. FIDA-U on the other hand demonstrated commitment to addressing intersectional discrimination and promoting diversity and empowerment.



Girls and women with Albinism having a great time at the event

AWARENESS & EDUCATION

Strategic Objective: To raise levels of awareness and mindset change that facilitates a positive conducive community for persons with albinism

Albinism Umbrella seeks to combat pervasive myths, misconceptions, and discrimination surrounding albinism. By prioritizing education and awareness raising, we aim at challenging harmful stereotypes, promote understanding, and foster acceptance within communities. Through targeted educational campaigns, advocacy efforts, and the dissemination of accurate information about albinism, Albinism Umbrella also seeks to create a supportive and inclusive society where persons with albinism can live with dignity, free from prejudice and discrimination.

These sessions raised awareness on; albinism, demystified myths and misconception around albinism, and advocated for inclusive education, active participation of persons with albinism in development processes. The sessions also enabled persons with albinism to engage with key stakeholders including; school community and the local authorities.

Community Information and Awareness Sessions

During the course of the year, Albinism Umbrella held community information sessions reaching a total of 4,705,190 people. The sessions took a form of school outreaches, community dialogues, radio talk shows and health outreaches.



Participants attending one of the outreaches organized by Albinism Umbrella in Kyegegwa district.

School outreaches

Albinism Umbrella in collaboration with Mengo Hospital-Low Vision Department to extended awareness, skin and eye care services to 21 schools reaching, 23 learners and 4876 school community members (including learners, teaching and non-teaching staff).



In picture one, Albinism Umbrella and Mengo Hospital staff making a school visit and providing assistive devices to a learner with albinism in picture 2

The awareness sessions equipped the school community with knowledge on albinism and the learning needs of pupils with albinism so as to create a safe learning environment where pupils can thrive and complete their studies. Eye care services ranging from eye care awareness sessions, eye checkups, visual enhancement devices, sunscreens and wide brimmed hat, were also provided to children with albinism thereby promoting their quality of life.

Community dialogues and outreaches - creating an environment where the rights of persons with albinism are respected.

A dialogue meeting with leaders from Kampala and Wakiso, reaching a total of 67 (41F, 26M) leaders. The dialogue engaged District Chairpersons, District Community

Development Officers, Counsellors of Persons with disabilities, Social workers, cultural and religious leaders.

The dialogue helped Albinism Umbrella to assess the leaders' perception about albinism and also paved way for awareness raising and unpacking the "unknown about albinism".

From the engagement, leaders pledged to support groups of persons with albinism in accessing special grant from Ministry of Gender Labour and Social Development (MGLSD), disseminating information about albinism in community meetings and to join the albinism fraternity in commemorating the International Albinism Awareness Day (June 13th).



Mr. Hassan Mulondo, one of the representatives of persons with disabilities, articulating issues and concerns of persons with albinism at Rockstone Hotel in Wakiso District.

Group photo of participants after the dialogue at Rockstone Hotel in Wakiso district Radio and Television talk shows

Albinism Umbrella conducted two (2) television talk shows and two (2) radio talk shows, reaching an estimated total of over 4.5m people.

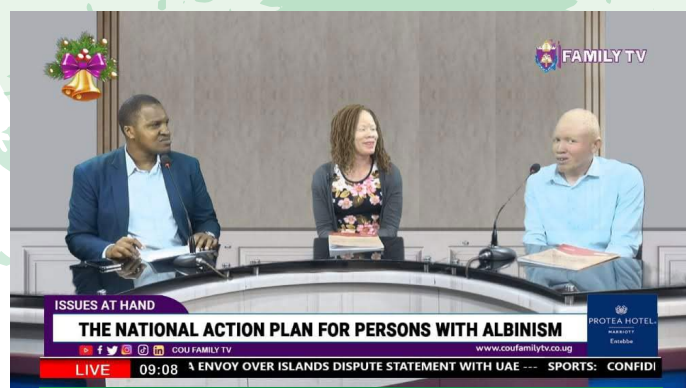
In 2023, the Executive Director of Albinism Umbrella was hosted on **NTV-Uganda's Mwasuze Mutya program (A popular TV program which provides a platform for engaging discussions, interviews, and insights on various topics)** and



Ms. Olive Namutebi narrating her experience as a person with albinism and a human rights advocate, at NTV Uganda

discussed her personal journey as a person with albinism. This interview provided a platform for her to share her experience, challenges, and triumphs, offering viewers a deeper understanding of the realities faced by persons with albinism. The show provided an opportunity for Albinism umbrella to create awareness about albinism on a national platform and to inspire persons with albinism and the country at large to embrace albinism.

On the other hand, **Family TV and Mama FM** in Kampala shows aimed to unpacked the National Action Plan on Albinism, highlighting its key components and relevance in enhancing the rights of persons with albinism. The existing imbalances in education and health services delivery were also profiled.



Mr. Paul Semwogerere and Ms. Phiona Nantaba from Albinism Umbrella, discussing the different issues on albinism, at Family TV in Kampala

Albinism Umbrella also held a talk show at **Centenary FM in Masaka** district ahead of the 2023 International Albinism Awareness Day which served to create awareness about this commemoration and its purpose. The show also contributed towards combating stigma and discrimination and to promote inclusivity by providing insights into the challenges faced by persons with albinism and the importance of raising awareness about their rights and needs.

Development and dissemination of Information Education and Communication materials

We designed, developed and disseminated IEC materials reaching over 5 million people. 15000 flyers, 15000 posters, 700

t-shirts, 300 wide brimmed hats, 112 copies of Annual reports, 349 copies of the National Action Plan on albinism booklet and 200 copies of the albinism health hand books. Dissemination and distribution took place in schools, health centers, partner organizations, donors, rights holders and on the streets of selected cities (Kampala & Masaka). The materials, in English and local languages contained different messages addressing myths and misconceptions about albinism as well as information on health and learning issues for persons with albinism.



In the photo above, are some of the Albinism Umbrella staff pinning posters with different messages/information about albinism on the streets of Masaka

SOCIAL PROTECTION AND SOCIAL JUSTICE

Strategic Objective: Develop the breadth and quality of persons with albinism to favorably compete in the market place; We recognize the systemic barriers and inequalities faced by persons with albinism in accessing economic opportunities and social protections. We therefore seek to address these challenges by advocating for inclusive policies, programs, and initiatives that promote the economic empowerment, skills development, and social inclusion of persons with albinism, hence enhancing equal opportunities and equitable society for all.

Governance and leadership;

We held the Annual General Meeting (AGM) on April 14th, 2023 at Fairway hotel to demonstrate our commitment to inclusive governance and stakeholder engagement.



Members from different regions taking part in the AGM that happened at Fairway Hotel in Kampala

The meeting that was attended by 54 (28F,26M) participants served as a vital platform for transparency and accountability, offering members updates on organizational performance and future plans.

Key highlights included discussions on achievements, challenges, and strategic directions, fostering collective decision-making and alignment with members' needs. 2023 also marked the end of tenure for the current board, and elections for the new board will be one of the highlights of the AGM-2024.

Capacity Strengthening for key stakeholders

Self-Awareness and Self-Acceptance/ Advocacy (SASA)

Albinism Umbrella trained 36 (20F,16M) persons with disabilities in the districts of Kamwenge and Kyegegwa in SASA to facilitate a deeper understanding of individual strengths, weaknesses and to encourage disability acceptance and foster a positive self-image. Emphasis was put on concepts like appreciation for oneself, self-care and empowerment, self-identity and self-advocacy which enhanced a sense of self-worth and confidence among persons with disabilities. During the training, the DCDO-Kamwenge- Ms. Harriet Niyongira advised participants to embrace government programs which target the financially vulnerable communities so as to boost their household incomes.



Participants undergoing group discussions during the training on SASA at Cape Hotel

Training on Safeguarding

Albinism Umbrella Board, Staff and volunteers participated in a 3 days safeguarding training organized by the secretariat and facilitated by Uganda Child Rights NGO Network(UCRNN). The training emphasized safeguarding risks and their implications and the role of the safeguarding policy. From the training, Albinism umbrella has been able to strengthen its safeguarding policy and practices, ensuring the safety and well-being of its members and stakeholders, particularly vulnerable persons with albinism.

LINKING WITH THE GLOBE: A KNOWLEDGE AND EXPERIENCE SHARING JOURNEY



Ms. Maureen Orogot taking staff, Board and volunteers through the training, at Albinism Umbrella premises

Socio responsibility, transparency and accountability.

Community Score Card

We partnered with Kitagata hospital-Bushenyi to assess health care service delivery, address healthcare disparities and improve outcomes for persons with albinism. The transparent discussion and feedback exercise that engaged 37 participants (19F, 22M),



Participants taking part in the exercise at Kitagata Hospital

identified gaps in healthcare services and derived interventions to enhance awareness of the needs of persons with albinism and to deliver inclusive and responsive health care services.



Photo showing some of the medical staff that participated in the exercise

In today's interconnected world, organizations operate within increasingly complex and dynamic environments, requiring them to adapt swiftly to emerging trends, challenges, and opportunities. By facilitating the exchange of knowledge and experiences, this promotes learning, fosters strategic partnerships, and fosters a culture of continuous improvement within organizations, ultimately contributing to the long-term success and impact in addressing societal needs and advancing common goals.

Harvesting Learning for Citizen-Led Accountability Action and Impact

In 2023, Albinism Umbrella, one of the six VOICE grantees of the "From Open to Inclusive Governance" program, actively participated in a series of workshops aimed at advancing citizen-led accountability and inclusive governance. Notably, our involvement in the **"Harvesting Learning for Citizen-Led Accountability Action and Impact"** workshop in Nairobi showcased our commitment to learning and sharing experiences.



Participants from all the 6 VOICE Project teams in Africa, pose for a group photo with their facilitators and some of the VOICE project staff

Through interactive sessions and practical methodologies, key lessons were articulated, focusing on storytelling, advocacy messaging, and data visualization. The workshop emphasized empowerment, networking, inclusivity, and sustainability, capturing the collective efforts of VOICE grantees towards fostering positive change and empowering communities.

African Linking and Learning Festival.

This was hosted in Nairobi, Kenya, as a dynamic platform for 45 delegates from 10 Grantee projects across East, West, and Central Africa, alongside VOICE representatives and The Constellation. The festival aimed to celebrate achievements and milestones in the pursuit of an inclusive global dream, fostering reflection among grantees and identifying opportunities for further improvement. Through sharing experiences, developing a roadmap for future action, and documenting key learnings, the event significantly contributed to the development of a global dream *"An inclusive world of just and harmonious society where human rights are enjoyed, respected and promoted through the diversity of their intersected identities, free from discrimination and violence while everyone is meaningfully participating in the dynamic transformation into an empowered community with justice and living in harmony with the nature."*



Albinism Umbrella team making a presentation on its linking and learning journey in picture one, as it pitches some of its work during a market place session in picture 2

The Annual Civil Society Convention

Albinism Umbrella was privileged to be a part of the 2023 convention that provided a platform to stakeholders from Civil Society, government and the private sector to network and show case the positive contribution of Civil Society to Uganda's development agenda. The convention facilitated a multi-stakeholder dialogue, reflecting on stumbling blocks and challenges of the sector, and identifying potential solutions.



During the event, Albinism Umbrella was among the 25 CSOs that showcased their success stories and programs, in a market place session where they had a close interaction with the Minister of Internal Affairs, Maj. Gen. Kahinde Otafiire, who was the Chief Guest. This provided us with a valuable platform to showcase our success stories and programs, engage with key stakeholders, and raise awareness about the challenges faced by persons with albinism.



ORGANIZATIONAL CAPACITY DEVELOPMENT

The conclusion of Strategic Plan 2018 – 2023

In the year 2023, Albinism Umbrella completed its first 5-year strategic plan (2018-2023). The period was largely one of pioneering new ways of working, putting together policies and structures, positioning the organization to provide advocacy for persons with albinism at high policy making levels and bodies; generate data on the actual status of persons with albinism in the country as a benchmark for evidence based programming, and raising awareness in regards to the human rights and social justice issues that surround the albinism community. The plan focused on 4 key strategic pillars that is; Health, Livelihood, Security and Social Justice. The current strategic plan (2024-2028) shall focus on two strategic drives -Partnership and Empowerment.

Accessibility audit for Albinism Umbrella new office premises

Albinism Umbrella undertook office accessibility audit which revealed that the offices are only 30% accessible calling for adjustments. We have instituted several improvements such as procuring and installing visibility items, fixing standard door handles, building ramps, increasing on premise lighting among others. This has enabled Albinism Umbrella to be disability accessible, in consonance with SDG 11 and Articles 2 and 9 of the Convention on the Rights of persons with Disabilities (CRPD).

Website review

In 2023, we conducted a comprehensive review of our website with the intent of enhancing user experience, accessibility, and information dissemination. With this, we envisage heightened visibility, increased engagement with stakeholders, and the facilitation of greater connections within the albinism community, ultimately empowering persons with albinism and advancing the organization's mission and vision. Following the revisions, there is a registered increase in our social media engagements on all our platforms and visits to the website.

Acquisition of a project vehicle

Albinism Umbrella with support from Christian Blind Mission is implementing a 3-year Sustainable Inclusive Economic Livelihood and Eye Health project in the districts of Kyegegwa and Kamwenge. In 2023, we obtained a vehicle to facilitate efficient transportation of personnel, equipment, and resources to project sites, enabling timely delivery of services and support to beneficiaries. There is an improvement in the organization's operational capacity, and a smoother execution of project activities.

OUR STAFF



Olive Namutebi

Executive Director



Janepher Nanyondo

Programme Officer



Phiona Nantaba

Project Officer



Yona Binagaijo

Project Officer



Happias Tumuranze

Project Officer



Ambrose Henry Idwarit

Finance & Admin Officer



Paul Ssemwogerere

Front Desk Officer



Daniel Lubuulwa

*Transport &
Logistics Officer*

OUR BOD



Simon Peter Okwi

Board Chairperson



Moses Mukuru

Vice Chairperson



Juliana Nantaba

Board Secretary



Brenda Boonabaana

Board Treasurer



Isaac Kyazza

Board Member



Isabella Akitenge

Board Member



Barbara Anyinge

Board Member

DEVELOPMENT PARTNERS



2023 IN PICTURES



Dialogue with the school head teacher on Inclusive learning



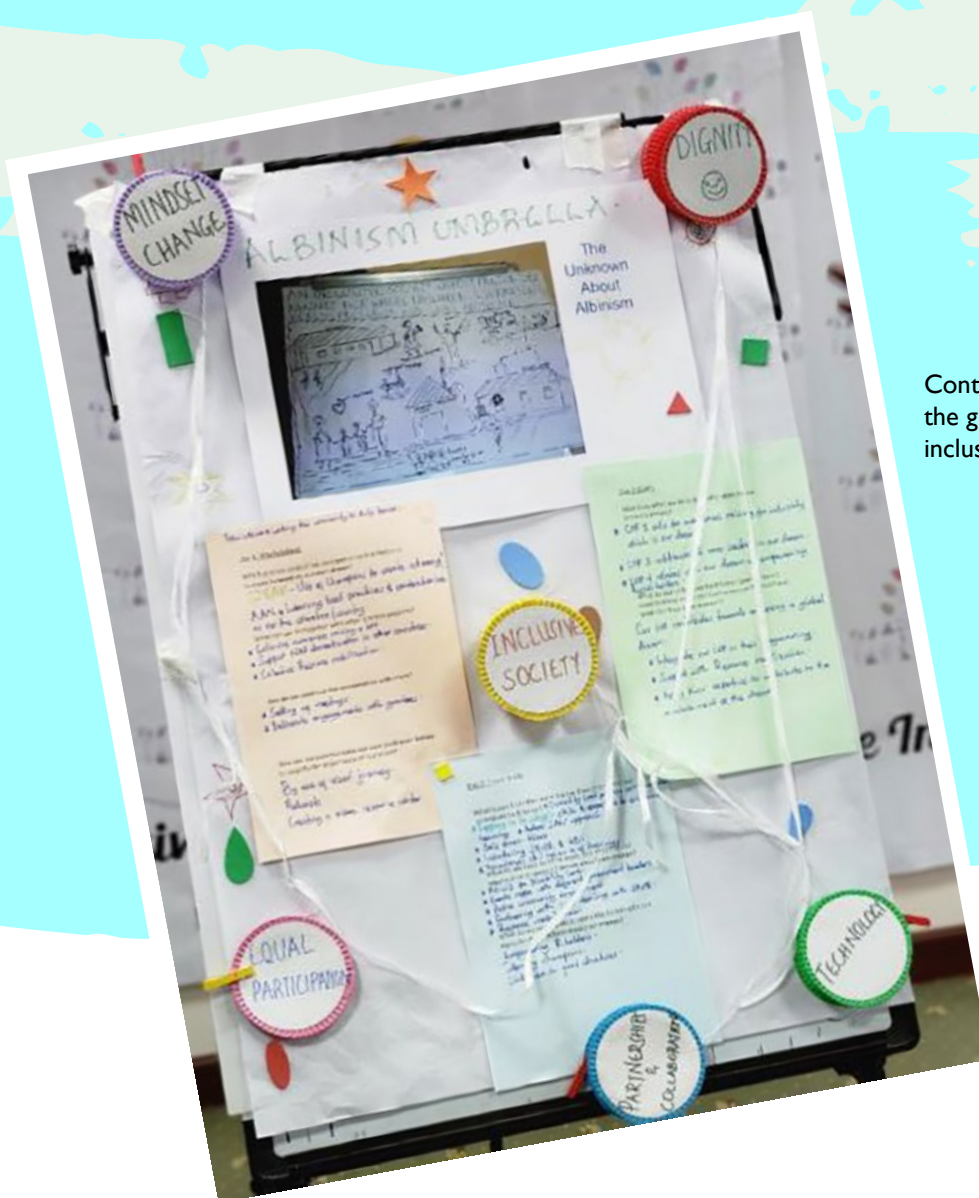
Sharing of learning experience by a learner with albinism



Rights holders having fun during the celebration of IAAD in Masaka



Ladies and girls with albinism having a good time while celebrating 16 DOA



Contributing to the global dream of inclusivity

STATEMENT OF FINANCIAL POSITION
For the year ended 31st December 2023

Particulars	Note	31-December-2023 Ushs	31-December-2022 Ushs
Income			
Grants income	2.1	738,193,600	656,879,643
Other income	2.2	95,283,475	156,310,000
TOTAL		833,477,075	813,189,643
Expenditure			
Program costs	2.3	369,400,891	365,539,963
Staff costs	2.4	195,910,379	136,996,640
Administration costs	2.5	130,384,521	40,519,367
Finance costs	2.6	3,545,672	1,768,237
TOTAL		699,241,463	544,824,207
SURPLUS FOR THE YEAR		134,235,612	268,365,436

Particulars	Note	31-December-2023 Ushs	31-December-2022 Ushs
ASSETS			
Non-Current Assets			
Property and equipment	2.7	201,694,154	72,039,150
Intangible asset	2.8	2,816,091	-
		204,510,245	72,039,150
Current Assets			
Cash and cash equivalents	2.9	362,219,316	352,400,251
Advances	2.10	6,634,330	-
		368,853,646	352,400,251
TOTAL ASSETS		573,363,891	424,439,401
RESERVES & LIABILITIES			
Reserves			
Accumulated fund		545,857,360	414,121,570
Current Liabilities			
Trade and other payables	2.11	27,506,531	10,317,831

TOTAL RESERVES AND LIABILITIES**573,363,891****424,439,401**

The financial statements were approved by the Board of Directors on ...**28th.../March.... /2024** and were signed on its behalf by:

CHAIRPERSON**TREASURER****EXECUTIVE DIRECTOR**



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