



ALBINISM UMBRELLA

ANNUAL REPORT 2020



Remarks from the Board Chairperson

Greetings from the Board of Directors of Albinism Umbrella (AU). I take this opportunity to thank the members of the AU, development partners and the secretariat whose collective effort has enabled us to steer a vibrant programme during the year albeit the COVID-19 challenges.

During the year, we focused on strengthening governance structures and policies, improving the effectiveness of the secretariat, resource mobilization, strategic partnerships and advocacy. I am happy to report that we are making progressive strides towards delivering an effective and responsive programme to our members. As the year comes to an end, I am pleased to note that AU has a functional board with a charter to guide its operations. The key governance structures; the general assembly, the board and management/secretariat are in place and fully functional. The key policy documents are now in place including; the constitution, human resource, finance and, Monitoring and Evaluation manuals. We have a strategic plan which informs our annual and quarterly implementation plans.

Our programming is steadily expanding with new activities coming on board like countrywide spatial mapping of PWA. We have maintained partnerships with key agencies of government and development partners. The AU agenda is increasingly gaining visibility in the policy arena at national and global levels. Our performance could have even been better than what we have posited had it not been for COVID-19 which has affected our operations.

In the coming year, we are going to focus on increasing the momentum in our programming and strengthening systems for finance, governance, human resources and, monitoring and evaluation. We will also roll out actions that drive greater involvement of people with albinism in development processes at different levels of government. We are going to be focusing on actions that empower and transform the lives of the AU members.

Finally, we are grateful to the AU members for entrusting us with the responsibility of stewarding their interests in the different spaces. We take the AU work as our humble service to the underprivileged people with albinism and their families. We are grateful to the different agencies of government for supporting our efforts. We are also grateful to the development partners who have supported our work. We undertake an enduring commitment to steer the AU vision while we still have the mandate.

Solidarity!

Moses Mukuru, Ph.D.
Vice Chairperson AU BoD



Remarks from the Executive Director

Dear Friends,

This is an exciting time to share some of our progress for the year 2020 which was marred by the Covid-19 pandemic. I am certain many of us are on the way to recovery from the devastating waves we have been through. The disruption has brought changes in the way we do our work which we must abide by as a new normal. We mourn with those who lost loves and may the God Lord comfort you.

Albinism Umbrella was able to approach the Office of the Prime Minister and secured food relief for PWA families in Kampala and Wakiso. United Nations Human Rights provided the transport to reach these homes which was a big support during the lockdown.

In spite of difficult times, we were fortunate to sign on a global grant from Voice to carry out spatial mapping for the rest of the country adding to the Eastern region earlier done in 2019. Disability Rights Fund and GIZ have also continued to support us in our work providing the needed capacity support. We were able to register other milestones like acquiring the Quick books accounting software making our reporting easier. The Parliament fundraising walk was also held in January 2020 and we now have a cumulative total of Ugx One hundred forty million (140m) from the four walks. We also carried out a fanatical literacy training in Luweero and formed regional structures in Bundibugyo.

As we brace for a new year, we call upon you to partner with us to increase awareness about the albinism condition, provide sunscreens, support our activities in any way possible. As the world gets more digital, please like and share our work on the social media platforms to increase visibility of Albinism Umbrella.

OLIVE NAMUTEBI
EXECUTIVE DIRECTOR



Building a society in which People with Albinism are dignified.



HER STORY

Albinism Umbrella was established in 2015 and fully certified in 2017 as a Non-Governmental Organization that consists of human rights defenders, people with albinism and all other albinism well-wishers with the ultimate aim of having a joint voice for all persons with albinism in Uganda. It was established to empower persons with albinism to fully engage in social-economic activities that directly improve their living conditions while promoting and protecting their lives.



Vision

A society in which people with albinism are dignified and realize their full potential to participate and steer the development processes.



Mission

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



Strategic Goal

To be the partner of choice for persons with albinism in Uganda, ensuring that their lives are protected, their livelihood supported and their dignity promoted.



Objectives

- 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

Who we work with

Community Based Organizations

Luwero District Albinos' Association

Albinism Association for Development- Kampala-Wakiso

Lira Albinism Association

Dorcas Tabitha Charity

Asante Judith Albinism Support Organization Uganda

Albino Organization for Bundibugyo and Ntoroko Districts.

Women and Children with Albinism (WACWA)

Source of the Nile Union of Persons with Albinism (SNUPA)

Current Donors

Disability Rights Fund-DRF

Civil Society in Uganda Support Programme (GIZ) with financial support of the European Union and the German Cooperation

VOICE- OXFAM Novib

Partners

The United Nations Commission on Human Rights

Government institutions

The Parliament of Uganda

Ministry of Gender, Labor & Social Development

The office of the High Commission for Human Rights

The Equal Opportunities Commission

Uganda National Association of Community and Occupational Health- UNACOH

Mengo Hospital

Uganda Women’s Network-UWONET



Our Theory of Change



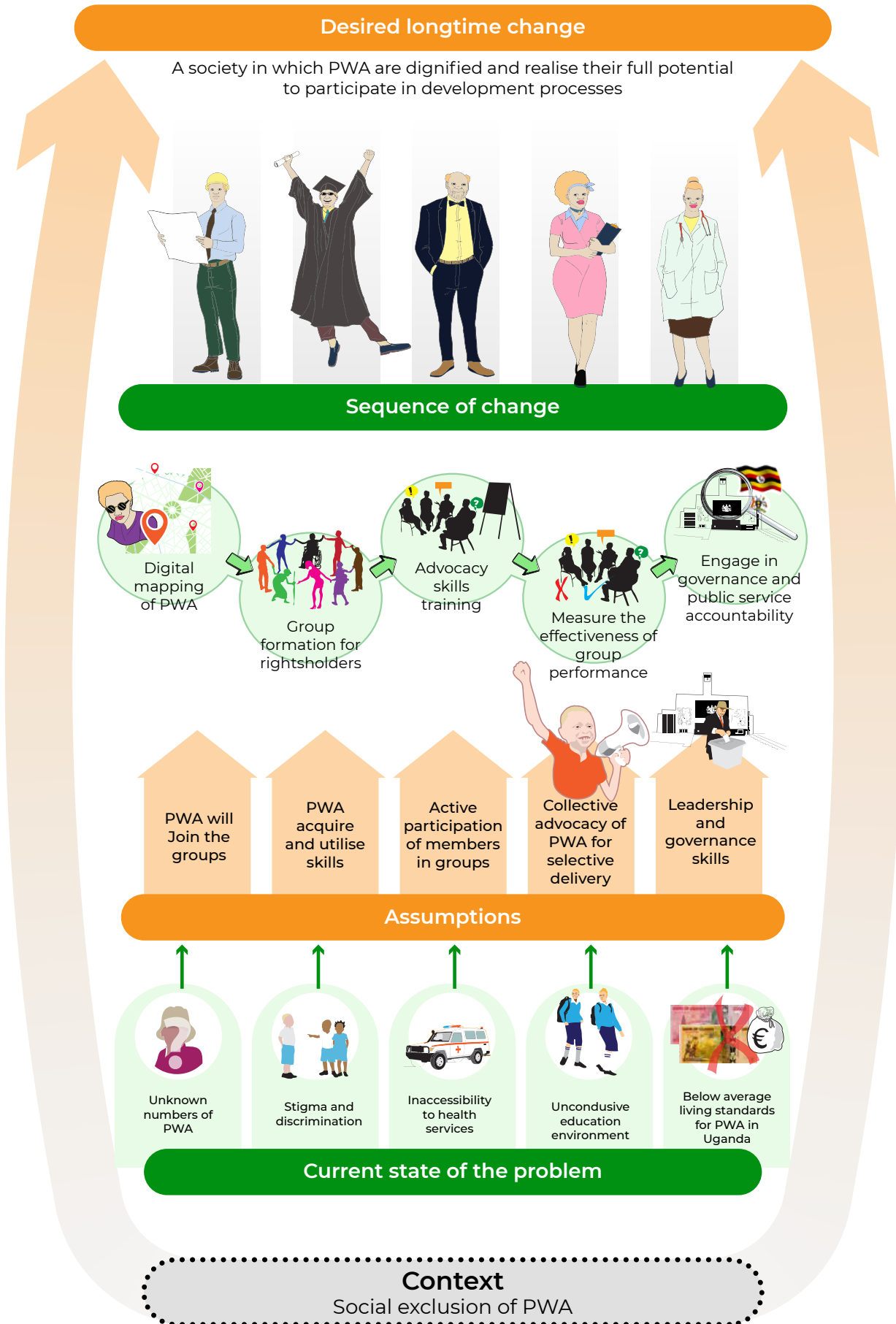
Albinism Umbrella envisions an ideal society in which People with Albinism are dignified and realise their full potential to participate and steer the development process. To have this realized, certain pathways must be utilized. The pathways will call for a number of action strategies and activities.

Albinism Umbrella realizes that for the theory of change to be realized, there is need to ensure that the current bottle necks are removed from the entire programming process. This calls for the engagement and participation of community members at all levels in the development process. It is also critical to appreciate that the realisation of this theory of change will require the engagement, participation and support from different players and development partners illustrated in figure 1.

- This Theory of change will guide the planning, implementation, monitoring and evaluation process of all programmes, projects and activities at Albinism Umbrella.
- It will act as a foundation for guiding all the M&E activities.
- It will guide strategic plan evaluations and confirming whether the differences and change Albinism Umbrella causes can be attributed to the interventions emerging from the pathways, notwithstanding the environmental constraints, both envisioned and non-envisioned.



Figure 1: The Albinism Umbrella Theory of Change





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2020

A YEAR IN REVIEW

Despite all the unanticipated challenges that manifested in the year 2020, Albinism Umbrella beat all odds and made a way to the point of triumph. We utilized strategic spaces for fronting issues concerning albinism and facilitated processes of inclusive participation for persons with albinism particularly in service delivery. 2020 saw the structures of Albinism Umbrella getting firm internally and externally with significant growth in partnerships and influence to human rights and policy actors.

Summary of achievements by organization objectives/ Areas of focus.

Objective/Area of focus	Achievements
1 To put persons with albinism's rights and well-being at the heart of policy makers.	Albinism Umbrella participated in the 2020 fundraising walk for the construction of a rehabilitation center for persons with albinism. Happening annually during the Parliament week. Over shillings 100 million has been collected.
	We also successfully lobbied and secured relief food for persons with albinism from the Office of the Prime Minister. This was following the country lockdown by the government to prevent the spread of Corona Virus.
	Albinism Umbrella participated in a virtual Celebration of the International Albinism Awareness Day
2 To give a voice to persons with albinism.	Albinism Umbrella extended financial literacy trainings to groups of persons with albinism to promote improved livelihood. 52 people in 4 groups benefited in these trainings.
3 To build a community of professionals that put issues of albinism within their work.	To provide legal support to the albinism community, Albinism Umbrella went in to partnership with BareFoot Law, an NGO that empowers people with free legal information. Other partners like Christian Blind Mission and Mengo Hospital, Eye department to be precise are in progress.



<p>4</p> <p>To develop the local persons with albinism network in order to deliver a powerful force for change</p>	<p>Successfully established Albinism Umbrella structures in Bundibugyo, Kampala, Luwero and Wakiso districts. This helped in strengthening Albinism Umbrella structures in different regions.</p> <p>Albinism Umbrella continued with the mapping and profiling exercise of persons with albinism in the remaining regions of Central, West and North. So far, clearance from the Research Ethical Clearance, district pre-visit and study tools pre-testing have been achieved.</p> <p>Participated in a knowledge exchange activity with AMPA one of the VOICE grantees in Bamako Mali. This steered up linking and learning process and best project implementation practices for both albinism Umbrella and AMPA.</p>
<p>5</p> <p>To build and strengthen albinism Umbrella for institutional sustainability</p>	<p>Development of a Constitution. Albinism Umbrella managed to put together some fundamental principles for good governance. This has shaped organizational operations and supported partnerships development.</p> <p>Albinism Umbrella held its first ever Annual General Meeting. This saw the election of a fully constituted Board and approval of the Constitution. For the past years, Albinism Umbrella had an interim Board that was supporting its operations.</p> <p>It conducted a successful Stakeholders' engagement meeting geared towards advocacy. 31 delegates from ministries, development partners, NGOs and policy actors engaged in a discussion about the plight of persons with albinism and how albinism umbrella can be supported to promote a dignified life for this community. The Minister for Elderly and Disability joined by other partners pledged to support albinism issues.</p> <p>Policies for institutional governance were developed like Child Protection Policy. This has improved on organizational operations.</p> <p>Continued documentation and Albinism Umbrella visibility through communications platforms such as website, social media platforms.</p> <p>Albinism Umbrella secured an accounting system. This has improved Albinism Umbrella financial operations</p>



Activities implemented in 2020 as per the developed work plan and Albinism Umbrella areas of focus

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

a) 2020 Fundraising Walk with the Parliament of Uganda

In 2016, the parliament of Uganda initiated the Annual Parliament Week program with the purpose of giving the general public an opportunity to meet and engage with their Members of Parliament and participate in a plenary sitting to discuss issues of concern. The program is kicked off by a fundraising walk towards the construction of a Rehabilitation Centre for Persons with Albinism in Uganda. This year, the event was officiated by the Speaker of parliament Rebecca Kadaga, Leader of Opposition in Parliament Betty Aol Acan, Government

Chief Whip Ruth Nankabirwa, other Members of Parliament, representatives from various ministries, departments and agencies, private organizations and religious leaders.

Shs54 million was raised and Clerk to Parliament said that the funds from the previous three years will be used to purchase land where the center will be built. "The money to deposit on the land is available and Parliament is in the process of identifying land without encumbrances," said the Clerk. It should be noted that a sum of shillings 5 billion is required to make this dream come true.



The Speaker of Parliament the RT Hon Rebecca Alitwala Kadaga flagging off the parliament week with a fundraising walk on 20th January, 2020.



Points to note from the day.

The Speaker of Parliament;

- Appealed to the government to make a deliberate effort towards compiling data for persons with albinism while carrying out National Census to help in planning for their special needs like healthcare and education.
- Called upon the Local Council leaders to make it their responsibility in knowing the number of children with albinism in their areas for easy planning in their respective schools.
- Was concerned about the continued taxation of sunscreen and other protective gears for persons with albinism even after parliament scrapped off the taxes.

The Government Chief Whip, pledged to be a goodwill ambassador in cabinet for policies related to issues of persons with albinism. "I will look in to it that taxes are removed from sunscreens which persons with albinism find costly and will make a monthly contribution of One Million Shillings during my reign" she added.

Key notes from the Executive Director

She applauded Parliament's efforts in addressing the plight of persons with albinism saying that their condition has been recognized under the 2019 PWA Bill. However, there is still a challenge of inaccurate data which affects services for persons with disabilities. "A recent research carried out by Albinism Umbrella with support from Oxfam in ten districts of Eastern Uganda registered 263 persons with albinism. Those who did not want to be counted were left out thus making the census inaccurate" Ms. Namutebi said.

She also said that the research found out that 72% persons had issues with eyesight but only 2% had received treatment, 68% did not know the cause of albinism implying that they are prone to believe anything. She concluded by appealing to government bodies to join Parliament in advocating for their wellbeing adding that Persons with albinism still face wide spread marginalization amidst costly equipment required to mitigate the effect of sunlight.



In the photo above, Ms. Namutebi the Executive Director Albinism Umbrella (right) followed by Government Chief Whip, Speaker of Parliament, Leader of opposition and the Clerk to Parliament Ms. Jane Kibirige watching an edutainment drama presented by persons with albinism.



b) Distribution of COVID-19 Relief food to persons with albinism

When COVID-19 cases emerged in Uganda, the government sought for measures to control the spread of the Virus in to the population. These included closure of learning institutions, ban on public gatherings and the climax was total lock down of the country. With the limitation on movements by people and a ban on transport means, unreachability to workplaces blocked people from earning a source of income culminating in to a number of challenges, hunger making it on the list.



In the photo above, Ms. Olive Namutebi the Executive Director Albinism Umbrella and Mr. Hassan Mulondo in the picture above confirming receipt of the food relief at Albinism Umbrella Offices.

However, the government of Uganda extended food support but could not reach out to every one while distributing this food relief. It was against this background that

Albinism Umbrella approached the Office of the Prime Minister (OPM) to lobby for food specifically for persons with albinism following the constant phone calls about cases of starvation and skin issues. It was on a good note that the request was granted and food relief (725 and 1000 kilograms of beans and posho respectively). Albinism Umbrella with support from the UN Human Rights (OHCHR) distributed this food to over 15 families and PWA were given sunscreens to protect their skins against sun rays.

Albinism Umbrella prides in this because our advocacy and lobby for food was recognized and we managed to support our community during the time that many had lost hope.

c) Participation in a virtual Celebration of the International Albinism Awareness Day (IAAD)- 2020

Unlike in the past years where people from Government Ministries, Departments and Agencies, development partners, Civil Society Organizations, Associations of persons with albinism and others could gather to recognize the IAAD, 2020 was celebrated differently with only a few partners participating virtually. This is because of the sudden break out of the COVID-19 pandemic pushed the government to put a ban on public gatherings.

IAAD is celebrated to address issues of discrimination, stigma and violation of the rights of persons with albinism hence with the growing use of technology, the world came together through a Webinar to appreciate and empower persons with albinism under the theme “Made to Shine”.

Albinism Umbrella was fully represented by the Executive Director, some Persons with albinism in an online engagement where several issues were discussed. The twitter handle was #AbinismDayUG and #madetoshine. Among the issues was the effect of COVID on PWA.



Ms. Namutebi on behalf of Albinism Umbrella handing over food relief to Women and Children with Albinism (WACWA) and to a family man with albinism.

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

a) Training of persons with albinism on group formation and financial literacy for improved livelihood.

Albinism Umbrella extended financial literacy trainings to groups of persons with albinism in Luwero, Wakiso, Kampala and Bundibugyo. This focused on the ability to manage personal/ group financial matters in an appropriate way as well as considering the knowledge of making appropriate decisions about finances, such as investing, financial projections, budgeting among others.

By the end of 2020, 52 people organized in 4 groups attained such trainings and acquired financial skills to support them in scaling up their income levels.



Pictures 1 & 2 here show a financial literacy training for persons with albinism and parents of Children with albinism facilitated by Ms. Macklean Amany



Strategic Area 3: To develop the local persons with albinism network in order to deliver a powerful force for change

a) Successfully formed regional structures in Bundibugyo, Kampala, Luwero and Wakiso districts

In 2019, Albinism Umbrella received an Organization Capacity Building grant from Disability Rights Fund. One of the objectives of the grant is to mobilize Albinism Umbrella members through forming regional structures. Initially, Albinism Umbrella was operating through Community Based Organizations without clear procedure of operation. With this grant, Albinism Umbrella has been able to mobilize and establish organized structures in different regions to improve Albinism Umbrella operations and service delivery to PWA. To achieve this, Albinism Umbrella through PWA representatives at the grass root mobilized members and presented the relevance of the initiative which includes;

- Having a system to provide members with moral support and help them achieve goals.
- Active engagement in Albinism Umbrella activities
- Receiving a sense of social security and safety among PWA
- Building self-esteem among members (PWA)
- Providing PWA with a refined sense of power.
- Helping in the process of successful goal achievement.

So far, Albinism Umbrella has mobilized 89 members including PWA and care givers of Children with albinism in the 4 structures of Bundibugyo (West), Lira (North), Luweero and Kampala- Wakiso (Central).



Participants of Kampala- Wakiso undergoing a training on the relevance of forming regional structures.



Group photo of Albino Organization for Bundibugyo and Ntoroko districts after meeting with Albinism Umbrella



Area of improvement:

Since formation, there has been improvement in service delivery, PWA database has been developed, Albinism Umbrella has actively engaged some members in its activities and project implementation to ensure participation. For example, in the Annual General Meeting, stakeholders' meeting, pre-testing of the study tool, district pre-visits and sunscreen distribution thus achieving the relevance of membership strengthening.

b) Started the journey of carrying out Spatial mapping and profiling of persons with albinism in the Central, Northern and Western regions of Uganda.

Just as mentioned earlier, 2020 emerged as one of the fruitful years for Albinism Umbrella based on the fact that we secured a grant from VOICE/OXFAM-global. Voice is an innovative grant facility that supports rights holders and groups facing marginalization or discrimination in their efforts to exert influence in accessing productive and social services and political participation. It is an initiative of and financed by the Ministry of Foreign Affairs of the Netherlands and executed by a consortium between Oxfam Novib and Hivos.

The “Unknown about Albinism” project is intended to map and profile households with persons with Albinism in Central, Northern and Western Uganda as a basis for advocacy and access to services. Districts include

Arua, Bundibugyo, Bushenyi, Gulu, Hoima, Isingiro, Kotido, Kitgum, Kayunga, Kasese, Kyegegwa, Kyenjojo, Kabale, Kabarole, Lira, Luwero, Masaka, Mpigi, Moroto, Masindi, Mubende, Mukono, Nebbi, Rakai and Oyam.

It is envisaged that the project will have a positive impact on the quality of life of PWA in the country by improving their health (including limiting cases of skin cancer) and achievement of education in the mainstream. There will be increased visibility and recognition of albinism as a disabling condition and the support structures created will facilitate advocacy access to services across the country. Ultimately the project will empower PWA by increasing their self-esteem and confidence and enhancing opportunities for them to participate effectively in mainstream development processes in the country.

So far, Albinism Umbrella has developed the study tool, pre- tested it to assess its reliability and ability to capture the appropriate information, made visits to all the 25 project districts for approval and finally secured clearance from the Research Ethical Clearance (REC). The actual implementation of this research activity will commence in April 2021.

c) Participated in a knowledge exchange activity with AMPA in Bamako Mali

The Association Malienne pour la Protection des Albinos (AMPA) is a Malian community-based organization set up to protect the rights and lives of people with Albinism.



The team from Albinism Umbrella participating in “The slam” activity organized by AMPA- Mali.



Albinism Umbrella is one of the beneficiaries of the Voice project under the Innovate and Learn wing. From over 15 grantees in Uganda, Albinism Umbrella emerged as one of the best performers under its innovative strategy of using Global Positioning System (GPS) to carry out spatial mapping of persons with albinism in 10 districts in Eastern of Uganda.

In 2018, Albinism Umbrella participated in the Indaba Conference that took place in Nairobi Kenya giving a platform to Ms. Olive Namutebi and Mr. Phillip Makasi to share their life experiences as persons with albinism and the strategy which Albinism Umbrella used to effectively implement the spatial mapping project. A conference of over 30 grantees from different countries in Africa appreciated and applauded Albinism Umbrella for the tremendous work and touching stories shared that left many grantees inspired and eager to pick a leaf, AMPA being one of them.



The team from Albinism Umbrella (two from right) posing for a picture with the 2020 Malian Mr. and Miss Albinism after the awarding ceremony.

With the experience from the Indaba Conference, AMPA invited a team of two people from Albinism Umbrella (Executive Director and Programs Assistant) to share experience and knowledge that could support them build capacity and improve on implementation of projects. Among other activities that the team participated in were the awarding of the 2020 Miss and Mr. Albinism Mali, “The Slam”, where PWA shared personal life stories, linking and learning with other voice grantees in Mali

and meeting with OXFAM- Mali Deputy Country Director. This took place between 25 & 28, October 2020.

The Experience and learning areas shared by Albinism Umbrella are not limited to contents of a strategic plan, report writing and sample templates, performance assessment tools, checklist for an activity, financial accountability practices, annual work plan template, documentation and filing, database management as well as accepting failures and how to go about them.



Ms. Namutebi sharing experience and Knowledge with VOICE grantees during the Linking and Learning activity.

Areas to note:

PWA under AMPA- Mali have a great sense of unity among themselves which has promoted confidence and self-esteem.

There is limited engagements of stakeholders including parents /families of children with albinism, the service sector, policy makers and the local community in PWA program activities.

The Executive Director of Albinism Umbrella advised AMPA to actively engage stakeholders since they need to embrace and appreciate the albinism fraternity something that can only be achieved through stakeholder collective effort as well as involving them in albinism advocacy and awareness programs like “The Slam” activity, International Albinism Awareness Day among others.



Strategic Area 4: To build and strengthen albinism Umbrella for institutional sustainability

a) Development of a Constitution.

A Constitution is a body of fundamental principles according to which an organization is acknowledged to be governed. Though still in its early stages, Albinism Umbrella is trying so hard to follow the right procedures and steps required by an organization to realize its set goals and targets.

In 2019, Albinism Umbrella secured a Capacity Building grant from Disability Rights Fund (DRF) to conduct an Annual General Meeting. This came at a time when it was in the process of developing a Constitution with support from Germany Cooperation (GIZ) thus the ideal moment to have the Constitution reviewed, articles amended if necessary and finally get approval from members during the AGM. Albinism Umbrella held its AGM on November 25, 2020 and had its Constitution approved with amendments as the overall governing body for Albinism Umbrella. This instrument will enable us to expand our network where this is a requirement.

b) Holding of the first Annual General Meeting and electing of Albinism Umbrella Board

Over the past years, Albinism Umbrella has been working with Community/District-Based Organizations to serve the albinism community but without clear membership, representation and definition of roles. In addition, was the existence of an Interim Board which served as the guiding body to the secretariat for over two years.

The Annual General Meeting was organized to give an opportunity to members to elect their representatives on the Board for the next three years, to make any changes to the Constitution and approval as well as updating members on the achievements and work of Albinism Umbrella. In attendance were persons with albinism representatives from across the country, the former Interim Board, Albinism Umbrella staff and a Consultant to guide and oversee the process.



Participants posing for a group photo during Albinism Umbrella Annual General Meeting.



Participants nominated for Board membership giving their profile during the AGM

Key points to note from the day:

She welcomed members to the first AGM. “Holding the AGM at such a time is a great achievement, I applaud the Executive Director for the dream which has unfolded in to the existence of Albinism Umbrella.” she said.

She recognized the partnership and support from DRF, GIZ and VOICE/OXFAM for sponsoring the spatial mapping activity that was carried out in 10 districts in the Eastern Region.

The Vice Chairperson thanked the Interim Board and the Secretariat for all the support they had availed in the past years, highlighting the successful development of the Strategic plan as one of the major achievements. She emphasized that the strategy would help Albinism Umbrella offer services in a strategic manner to shape the future it desires.

She thanked Albinism Umbrella members and regional structures for embracing Albinism Umbrella support and the Development Partners for their continued support. As the Interim Board hands over to the newly elected Board, she urged all the members to join the Board and support its effort in fulfilling its strategic intentions.



Ms. Allen Bonabana the Interim Vice Chairperson giving remarks and presentation of the Annual Report

In the same meeting, the Treasurer’s report was presented by the Finance and Administration manager, Mr. Henry Mujuni who took members through the financial report, the Comprehensive Income and Expenditure statements and the statement of Financial Position as the Board Secretary, Ms. Juliana Nantaba stepped in to present the Constitution. More emphasis, both in English and some local languages was directed on the Albinism Umbrella strategic objectives and who the membership must be. At the end of the session, members approved the Constitution with amendment.



The Finance and Administration Officer and the Interim Board Secretary presenting Albinism Umbrella Financials and Constitution respectively.

Though there was no criteria of who can be voted, the position of chairperson was ring fenced for PWA by the constitution. Regional balance and gender were also considered. The exercise was through secret ballot and saw many able PWA contest for different positions on the board which promoted democracy, inclusion for all and built a sense of ownership.

The moderator presented the new Board to the AGM and asked the new Board Chairperson to give her Inaugural speech. Ms. Allen Bonabana thanked members for entrusting them with the new positions and urged the newly elected board to work as a team in implementing the Albinism Umbrella strategy.



In picture one, the moderator, Mr. Robert Mugambwa facilitating the meeting and vote counting with Mr. Jackson Atria, DRF Consultant going on right after elections in picture 2



The picture above shows the newly elected Board by the 2020 Albinism Umbrella Annual General Meeting.



c) Held an advocacy stakeholders' meeting on November 27, 2020

With support from the Voice project under Oxfam, Albinism Umbrella is in the process of conducting a spatial mapping of PWA in three regions of Uganda including the Central, Northern and Western regions. This will be supplementing its first mapping in the 10 districts of Eastern Uganda carried out in 2018, hence attaining the National representative data.

A Stakeholders' meeting was organized to unveil the Albinism Umbrella newly elected Board and validate the assumptions and analysis of stakeholders' interest in profiling of PWA. The event was held on November 27, 2020 at the Fairway Hotel in Kampala Uganda. In attendance were the Chief Guest, Hon Sarah Kanyike, State Minister for Elderly and Disability, Commissioner in the Ministry of Gender, Labor and Social Development, Development Partners, the media and PWA, moderated by Mr. Robert Mugambwa, Program Development Consultant.



Participants pose for a group photo during the Stakeholders' Meeting.



Annual General Meeting



The State Minister for Elderly and Disability Hon. Sarah Kanyike addressing the meeting.

i. Remarks from the Chief guest

The State Minister for Elderly and Disability Hon. Sarah Kanyike was the Chief Guest for the meeting. After a brief personal profile, the Minister defined schedule 3 of the Persons with Disabilities Act which lists Albinism as a form of disability amongst the categories of disabilities. She mentioned that global studies reveal that 1 out of every 3,000,000 people is a PWA but the actual number is not yet known however, confirmation on the numbers of PWA may be availed by UBOS next year (2021), hence will be a more hopeful situation to Uganda and the Umbrella in particular.

“There is a serious need to sensitize the communities who must have a different mindset on PWA, as a Ministry, we shall continue supporting the Umbrella as long as it is willing to engage the Ministry.” The Minister mentioned how encouraging it is when groups are mobilized and communications made to the Ministry for this makes planning easy based on their needs.

“Presentation on the findings on the Spatial Mapping study gives hope to the PWA fraternity whereby they can receive the services they need, and then impact can be attained. With the coming of the International day of PWD on the 3rd of December 2020, efforts will be made to ensure that the Chairperson and the Executive Director attend “the Minister added.

The Minister appreciated the composition of the Albinism Umbrella Board, which she said had a diverse category of professionals and gives it a promising future that they will make impact and benefit the PWA. She concluded by encouraging PWA to always seek medical attention and also pledged to ensure there is better access to service delivery and inclusiveness.

Albinism Umbrella would like to extend her gratitude to the donors, partners, staff and stakeholders whose tremendous work throughout 2020 made it possible to transform lives as well as supporting advocacy work geared towards improving the status of PWA and their community.



ii. Albinism Umbrella background and current interventions by the Executive Director Albinism Umbrella

Ms. Olive Namutebi welcomed the invited delegates and thanked them for finding time to attend the meeting. She gave the Albinism Umbrella background which was set up as a voice for PWA in Uganda so that as a team, we can actively lobby and advocate for PWA inclusion and their families on the global forum for sustainable development.

iii. Interventions;

- Albinism Umbrella is now dedicated to increasing advocacy in a bid to ensure that Government starts recognizing PWA who are legally blind and have limited legal access because the laws of Uganda do not specifically include them as a discriminated minority group.
- With support from Oxfam, Albinism Umbrella has been able to map PWA in the 10 districts of Uganda given that there has not been information on the total population and distribution of PWA in Uganda.
- Albinism Umbrella was also able to lobby with the 9th Parliament and engaged in the Annual

Parliament Week program to have the Fundraising walk aimed at supporting PWA have their own Centre that would double as a skilling centre and host them as they make own sunscreens.

iv. Recommendations

- There is need for social support and addressing the issue of lack of information for PWA.
- There is need to ensure that school going children with albinism keep in school without stigma and discrimination.
- Policy makers should put emphasis on a National Action Working Plan for persons with albinism.
- Institutions like police and the general public ought to keep an eye on PWA whose security is not guaranteed.
- There is need to include persons with albinism in planning and all other government interventions.

She further shared the Regional Action Plan and the four pillars that it represents including Protection, Prevention, Promotion and Equity and concluded by saying that Albinism is not a disease neither is it contagious; know the truth and pass on the truth.



Ms. Namutebi, the Executive Director giving her remarks during the meeting.



v. Development Partners' remarks

Ms. Esther Kyoziira from the Disability Rights Fund gave remarks on behalf of the Development Partners. She expressed her delight in being present at the meeting that was the first of its kind for an organization as young as Albinism Umbrella and had gathered strategic personalities.

She gave an overview of the Disability Rights Fund, as one that is mandated to support advocacy by persons with disabilities to be active participants in decision-making in society and with government.

She mentioned that Albinism Umbrella, being an umbrella that brings persons with albinism to have better ways of addressing their challenges, makes it a good partner that will work with the Disability Rights Fund. "With the commitment from Albinism Umbrella and with their concerns well-articulated, Albinism Umbrella should be able to spark off a dialogue on social inclusion" Esther said. In her message to the new Board, she urged them to support the Secretariat to do its work and implement Albinism Umbrella activities.



Ms. Esther Kyoziira (on the microphone), the Programs Officer of Disability Rights Fund giving partner remarks.

vi. Unveiling the Elected Board and remarks from the Board Chairperson.



Some of the newly elected Board members being unveiled to the stakeholders meeting.



vii. Remarks from the Board Chairperson

Ms. Allen Bonabana appreciated all delegates, particularly the development partners for honoring the invitation to the meeting. She thanked the outgoing board where she also served as the Vice Chairperson for the great achievements during their tenure and also welcomed the new board.

She noted that as the new board of Directors, they have the right instruments to start off with, including the Constitution and Strategy. She mentioned that with the functioning board in place and with all the experience members have, they can strongly support the Albinism Umbrella committed secretariat. She concluded by saying that the nature of Albinism Umbrella has challenges with resources, it having no Income generating activity and as such will depend on mobilizing resources to run the organization hence the need for collective effort from the Board.

viii. Other key highlights from the day

Mr. Anatoli Muleterwa the Assistant Commissioner of Police in-charge of Community Policing said it is time for the society, to come together to protect PWA so that they can live a dignified life and not shy away from realities in life. "I thank the Minister for standing up to support the PWA in ensuring that they are nurtured and strengthened so that they do not give up on life. As police, we offer an open hand to all to ensure that engagements with the institution and the communities are strengthened thus, I appeal to each one of you to always support the police, stand up for patriotism and safe guard Uganda ensuring the stability of the country." Said the Commissioner.

On behalf of the Executive Secretary for National Council for Disability, Mr. Hassan Mulondo, the representative of persons with albinism gave a brief background about the



Mr. Anatoli Muleterwa in picture 1 and Mr. Hassan Mulondo in picture 2 giving their remarks.



Council as a Government Department that was formed in 2003 by an Act of Parliament to monitor programs that address the needs of persons with disability.

He urged persons with albinism to embrace the “Nothing About us Without us” slogan and added that the Council is ready to give support to the Albinism fraternity to see that issues are raised and followed up.

ix. Presentation of the Spatial Mapping research findings

Dr. Arthur Bagonza, the Co-Investigator on the Spatial Mapping that was conducted in the 10 districts of Eastern Uganda appreciated the numerous stakeholders that have developed policies that protect the vulnerable groups in Uganda.

The report on spatial mapping was a result of the numerous challenges that PWA faced including discrimination, stigma and even death due to myths and misconceptions surrounding their existence. The most critical situation is that no plans were made to help the situation because of the uncertainty surrounding their numbers, policies in place meant to protect them as well as the few organizations helping them.

Dr. Arthur reported that the study was done at the same time UBOS was doing the same study, an opportunity that presented itself through sharing approaches and findings. It was also revealed that in creating an intervention for PWA, it is more appropriate to have them work in groups and the best part is that the Ministry of Gender, Labor and Social Development has funds allocated to people in groups that meet up with the requirements. “This is a positive sign that PWA can be reached and empowered as long as they are mobilized and attached to a group” he mentioned.

Mr. Patrick Menya the Commissioner for the Elderly and Disability at the MGLSD shared information that there is now a National grant available for persons with disability (PWD) which to date has reached out to 1129 people and added that more funds have been made available totaling to four billion with a target of reaching out to over 800 groups. Groups of PWDs specifically PWA were encouraged to apply for the fund with a minimum of 5 PWDs, not exceeding 15 PWD and must have been registered at the Sub-county since they will be supervised by the Sub-county Community Development Officer. The groups can only get a maximum of five million.



Dr. Arthur Bagonza giving an over view of the Research project and findings



Secretariat

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

Board of Directors



Allen Bonabana
Chairperson



Moses Mukuru
Vice Chairperson



Brenda Bonabana
Treasurer



Juliana Nantaba
Secretary



Simon Peter Okwii
Member



Isabella Akiteng
Member



Barbara Anyinge
Member



INCOME AND EXPENDITURE STATEMENT

	2020	2019
	Ushs	Ushs
Income		
Grant from Oxfam	199,642,000	308,758,489
Grant from DRF	21,870,000	21,694,660
Other income – local contribution	2,082,005	-
TOTAL	223,594,005	330,453,149
Expenditure		
Program Expenses	91,437,707	164,864,375
Staff costs	58,756,960	79,715,000
Administration costs	28,082,938	46,432,630
Depreciation	1,211,750	1,211,750
TOTAL EXPENDITURE	179,489,355	292,223,755
SURPLUS/(DEFICIT) FOR THE YEAR	44,104,650	38,229,394

STATEMENT OF FINANCIAL POSITION AS AT 31 DECEMBER 2020

	2020	2019
	Ushs	Ushs
ASSETS		
NON-CURRENT ASSETS		
Property and equipment	982,000	2,193,750
	982,000	2,193,750
CURRENT ASSETS		
Cash and Cash Equivalents	99,287,333	39,454,944
	99,287,333	39,454,944
TOTAL ASSETS	100,269,333	41,648,694
RESERVES & LIABILITIES		
Accumulated Fund	87,434,333	40,148,694
	87,434,333	40,148,694
CURRENT LIABILITIES		
Trade and other payables	12,835,000	1,500,000
TOTAL RESERVES AND LIABILITIES	100,269,333	41,648,694



Audit Opinion as extracted from the audit report issued by Bawunha & Badebye Certified Public Accountants.

We have audited the financial statements of Albinism Umbrella, set out on pages 10 to 19 for the year ended 31 December 2020. The financial statements comprise of the statement of financial position, the statement of income and expenditure, statement of changes in reserves and statement of cash flows for the year then ended, and notes to the financial statements, including a summary of significant accounting policies.

In our opinion, the accompanying financial statements present fairly, in all material respects, the financial affairs of the organisation as at 31 December 2020, and of its financial performance and its cash flows for the year then ended in accordance with Generally Acceptable Accounting Principles (GAAPs), the requirements of the Companies Act and Non-Governmental Organisation Act, 2016.

THANK YOU

Co-funded by:



Implemented by:



**DISABILITY
RIGHTS
FUND**



Albinism Umbrella
Plot 1376, Block 213, 14 street
Kaweesa Bypass-Bukoto Kampala
P. O. Box 3262-Kampala, Uganda
Phone: +256 393 208 405,
Email: info@albinismumbrella.org
Facebook: <http://www.facebook.com>
Twitter: @albinismumbrella

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