

Beyond my Skin
The Benga Albino Program
Building of an Integrated Social Hall for Music and
Vocational Training for people living with Albinism around
Benga Mission



Location: Benga Mission, Nkhotakota District, Malawi.

Holder: Missionary Community of Saint Paul the Apostle
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Beneficiaries: People living with Albinism gene

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1. Introduction

People living with albinism have always been looked down upon especially in Africa. In Malawi and other parts of the Africa, statistic show people living with albinism have been attacked, murdered and mutilated based on incorrect ideas and misconception about body parts are sold for ritual purposes/witchcraft to supply charms and magical portion, to some to get rich and wealth (<https://www.aljazeera.com/news/2017/04/malawi-people-albinism-living-fear-170419064018308.html>) and also being hunted for their bones (<https://interactive.aljazeera.com/aje/2017/malawi-killed-for-their-bones/index.html>).

Due to such believes, Albinos are becoming an endangered race because they are being hunted down like animals, making them to be reclusive, timid and unconfident.

Albinism is a rare, genetically inherited condition that occurs across the globe, regardless of race, ethnicity, class or gender that affects pigmentation of the skin, eyes and hair. Albinism genes are carried by both parents and transferable from one generation to another. They are various categories of albinism but well known type is oculocutaneous albinism, which affects eyes, hairs and skin, which causes vision problems, skin burns and later skin cancer. According to last census of 2018, nearly 1% of the total population of 17 million people are people living with albinism in Malawi (140,000 people). The figures given by APAM of the people living with albinism in the Benga Parish catchment area is about 293 people however we suspect that there are much more who have not yet been counted for.

2. Summary of the Project

This present proposal intends to create a social hall where the people living with albinism or otherwise can have a space to interact and share ideas, and promote activities that will empower them and improve their living conditions. We are working within the framework of the strategic plan (2017-2022) designed by Association of Persons with Albinism in Malawi (APAM) to protect people with albinism from all forms of discriminations, violation and respecting their rights, access quality health care and education services (<https://www.reuters.com/article/us-malawi-election-albinism/malawians-with-albinism-to-fight-elections-in-bid-to-stop-killings-idUSKBN1JM2LO>). It focuses mostly on social and economic development, human rights, quality education, food security and nutrition to bring balance in the society and achieving sustainable development goals among people with albinism. Therefore this project intends:

- To promote recognition of the skills, merits and abilities of persons with albinism and other disabilities, and of their contributions to the workplace and the labour market;
- To create awareness of albinism and to promote and protect the rights of the people living with albinism; ^{[[L]]}_{SEP}
- Fostering at all levels of the education system, including in all children from an early age, an attitude of respect for the rights of persons with albinism and other disabilities; ^{[[L]]}_{SEP}
- Promoting awareness-training programmes regarding persons with albinism and other disabilities and the rights of persons with albinism. ^{[[L]]}_{SEP}
- Through art and music to foster acknowledgement of the persons with albinism in showing their talents that can be appreciated in the community at large.



3. Background Information

Missionary Community of St Paul the Apostle (MCSPA) is a Catholic Public Association of Christian Faithful formed by men and Women from different nationalities. The MCSPA is working in Benga, Malawi since 2012. Members of the MCSPA are also present in Kenya, Ethiopia, South Sudan, The Philippines and Mexico. The Benga parish through the support of benefactors has initiated this programme to try and alleviate the situation of the people living with albinism, in order to improve their situation and their total integration to the community. So far the persons who are benefitting from this programme have been 20 persons.

When the members of MCSPA come to Malawi, the first steps were made and a study of the area was done. The study revealed extreme poverty in the area. A total of 500 persons were interviewed: 50% being women and 50% men. According to the study 85% of the population in the area live off from agriculture. 56% of the population completed primary school education and 20% completed secondary school education. During this study it was also surprising to see a number of people living with albinism and who did not have any care or support. They lived in extreme situations with very poor clothing to protect them from the sun and with no sunscreen. Most of them are hidden in their homes because of the stigma. It was important therefore that some special attention be given to this group. Since last year therefore, a programme called *Beyond My Skin* was set up to care for the people living with albinism around Benga Parish. Until now, this programme has concentrated in providing protective clothing, sunscreen lotions, sunglasses and shoes to more than 100 people living with albinism. It has also been organising monthly meetings that more than 30 albinos together with their families. This programme has also organised two dermatological and surgical campaigns where several people living with albinism were screened and operated mostly on skin complications. Eye care is has also been organised where screening was done and some treatment given.

4. General Information About Malawi

Malawi covers 118,484 Km² with a population of about 17.5M people. It is a land locked country, bordering Tanzania to the North, Mozambique to the South, South-East and South-West and Zambia to the North-West. Being 840 Km long and an average width of 150 km, it is one of the smallest countries in Africa. The country counts with numerous mountains and plateaus, however the most important geographical feature is Lake Malawi. It is 585 km long and 75 km at the widest point. It has a total surface area of 29,600 km² and an enormous biodiversity. The Lake empties into the Shire River, which is a subsidiary of the Great

Zambezi. Taking into account that the total combination of lakes, rivers marshes and lagoons constitute 20% of the country it can be concluded that Malawi is not short of water and has great potential for agriculture.

Temperatures range from 30oC to 6oC. They vary according to the location and the season. They tend to be higher in the lowlands: Lake Malawi and the Shire River Valley and lower in the Highlands. There are three seasons: dry hot season (August to November), wet hot-season (December to April) and winter (May to July).

The autochthonous ethnic group in Malawi are the Chewa people they may derive from groups that migrated from Congo rainforest and gave rise to the Maravi Empire in the 15th C., which extended from the Southwest shores of Lake Malawi to the North. In the 16th C. they traded with the Portuguese. Its decline came in the 19th C. with the invasion of the Angoni from the Natal region in modern day South Africa. The second group to come were the Ayao from modern day Mozambique. Swahili traders came with the Ayao in search of slaves.



5. Justification of the Project

The UNHCR report indicates at least 20 people have been killed in Malawi since 2014. More than 150 people living with albinism abducted, rights violated, and graves exhumed. For example, parents with people living with albinism fear for their children safety, they end up spending time to guard and protect their children from hunters, this leads to less productivity in the family. Although APAM tries its best in protecting and fighting for the rights of Albinos, there is need for more efforts to protect them and to create awareness among them so that they could feel free in the society instead of living in fear and the odd stigma which makes them feel unaccepted in the society.

This situation has brought Malawi to a state of crisis. The frequency and intensity of the attacks has left all people with albinism living in a cloud of fear and uncertainty. The gravity of the situation was aptly highlighted to Parliament by the Chairperson of the Association of Persons with Albinism in Malawi (APAM). He stated, *“Last night I went to bed, not sure whether I would wake up in my own bed or not. I went to bed not sure I would wake up with my limbs intact or not. I went to bed; not sure I would witness one more beautiful sunrise or not. Not because I am terminally ill and that a doctor has given me a few hours to live, but because I and all persons with Albinism are being sought after, to be killed, our organs harvested and sold in the false promise of a bag of gold or silver. In the depth of this despair, when death is considered to be the end of my suffering, I will not be allowed to rest. Death will not bring me peace, because my tomb will be desecrated, my grave opened up for my bones to be harvested.”*

A report by Amnesty International conducted in 2015, links these beliefs and the subsequent attacks on high levels on *poverty, illiteracy* and *inequality*. According to the UNDP Human Development Report of 2017, Malawi’s Human Development Index is 0.477 and is ranked 171 out of 189 countries. Poverty levels remain high, with a majority population living off proceeds of rain-fed small-scale farming. Within such a challenging socio-economic situation, a belief in any *get-rich scheme* can be easily fuelled. Unfounded solutions to end poverty such as the killing and selling of albino body parts have thus spread to all parts of the country at an alarming rate.

Socio-economic empowerment of families of persons with albinism

The Malawian government organ that recently investigated the situation of the people living with albinism in Malawi, noted that persons with albinism have been targeted in attacks are often those in living in rural impoverished situations. The issues are as a result of various structural issues that drive families into poverty traps. Persons with albinism often have poor eyesight and limited access to health care. It is therefore difficult for them to progress in their education, leaving them with poor socio-economic standing in society. The attacks

have further compounded the situation, as persons with albinism are unable to carry out normal income generation activities as they live in fear of even going out of their houses.

There is therefore need to prioritize persons with albinism within the various social protection and integration programmes. This particularly includes; advocacy for the rights of the people living with albinism, income generating activities, social recognition and empowerment and education for the school going children.



6. Description of the Project

This project aims at setting up a Social Hall for the use as a resource centre for people living with albinism. This will create space to improve on the conditions of the people living with albinism. It will give them ability to fashion products, to work on their talents in art and music, to be known in the community and eventually to be accepted. The Social Hall will be a space to explore on their talents, in questioning their situation, inquiring about it, searching for means to address it, manipulating situations to accept it and experimenting ideas to embrace it. Music will be used as a language that allows them to **express** what is

happening around them in many senses, and to **reflect** the times and the situation in which they live so as to community to the world their feeling.

This project intends to include a **library** where the people with albinism and others can learn about different things of their situations and beyond. It will enable then to participate in the arts, and to explore their immediate world and the world at large. The library will be a space to encourage curiosity, innovation and problem-solving especially those within our community like lack of integration, since it will be a centre for cultural activities, access to information, knowledge building and possibilities of understanding. It will provide space of mutual connection and understanding of the people with albinism.

The Social Hall will create space for art and music. It will also create space for discussions where the people living with albinism and others will participate in bringing to life favourite stories and other forms of discussions that would stimulate forums and debates. This debate will hopefully lead to inclusion and acceptance. They will learn to work with others, and developing solidarity, emotional communication, empathy, etc. on both a musical and human level. Thus, through music and drama they can inspire such values as solidarity, non-violence, dialogue and unity, and it strengthens feelings of both self-confidence and confidence in others, as well as developing creativity and imagination.



7. Objective of the Project

The main aim of this project is to integrate and protect the rights of persons living with albinism to access quality education and health care services to improve their living standards.

People living with albinism are worried of being marginalized as they are discriminated within the society, unable to access education as they are insecure to go school, as they lack safety precautions at school and also suffers emotional abusive as they are not welcome to participate equally in the activities by their peers. Whereas grown up people with albinism are afraid to engage in socio economic activities, from past experience. They are not sure if they are hired for work or a plot to kill them, they usually prefer to hire another person to look after them, and this automatically affects and eliminates them from casual employment market, which leads to poverty trap.

The project home to build up a hall complete with toilets, dining room and a resource centre where people with can e actualised.

8. Beneficiaries of the Project

The main beneficiaries of this project will be the people living with albinism though it will also be open to other people as an integration means for people to live and appreciate the ones living with albinism.



9. Activities of the project

1. Create a space where the people living with albinism can actualise themselves and be integrated.
2. Help the people with albinism improve on their ability to communicate and be heard
3. To be able to be integrated into the society through economic activities and art.
4. The hall will create space of affective and knowhow of the people living with albinism as normal
5. Provide a secure space where the people living with albinism can actualise themselves and thrive
6. Increase awareness of the people living with albinism to be integrated and accepted in the society
7. To enable the society to be informed and aware of the situation and condition of the people living with albinism in their midst
8. For the people living with albinism to learn and be involved with income generating activities that keep them out of the sun
9. The hall will be rented out to generate income for other programmes

10. Budget of the Project

NO	CONCEPT	M.KWACHA	EUROS
1	Substructure Excavation	1,760,000.00	2,200.00
2	Concrete Work	1,120,000.00	1,400.00
3	Walling of substructure wall	1,840,000.00	2,300.00
4	Super structure	1,760,000.00	2,200.00
5	Roofing	1,600,000.00	2,000.00
6	Door and Windows	880,000.00	1,100.00
7	Plumbing	560,000.00	700.00
8	Finishing	1,120,000.00	1,400.00
9	Electrical work	722,500.00	850.00
10	Painting	360,000.00	450.00
	TOTAL BUDGET FOR THE WALL	11,680,000.00	14,600.00