JUST LIKE YOU!

Addressing Myths and Misconceptions on Albinism

UNITED NATIONS
HUMAN RIGHTS
OFFICE OF THE HIGH COMMISSIONER

JUST LIKE YOU

Addressing Myths and Misconceptions on Albinism

Introduction

Albinism is a widely unknown condition in Uganda and there are widespread myths and misconceptions around persons with albinism, particularly in sub-Saharan Africa.

Lack of knowledge and recognition of challenges specific to persons with albinism has deepened stigma, discrimination and lack of action to support their needs. This report is aimed at raising awareness on albinism and highlighting ongoing challenges faced by persons with albinism in Uganda.

The report addresses myths and misconceptions around albinism that affect the enjoyment of human rights by persons with albinism, including the right to health, education and employment. Further, the report gives an insight into societal discrimination experienced particularly by women and children with albinism and women who are parents, guardians and caregivers to children with albinism.

This report is guided by the 2019 Situational Analysis Report on Albinism in Uganda, published by the Office of the United Nations High Commissioner for Human Rights (OHCHR) in Uganda together with the Equal Opportunities Commission (EOC), and the 2017 Regional Action Plan on Albinism in Africa (RAP 2017-2021) developed by the United Nations Independent Expert on the enjoyment of human rights by persons with albinism and adopted by the African Commission on Human and Peoples' Rights (ACHPR) in July 2019.

I. BASIC FACTS ABOUT ALBINISM

What is albinism?

Albinism is a rare, non-contagious genetic condition that limits the production of a pigment called melanin, which gives colour to the skin, eyes and hair.

Affected individuals typically have very fair skin and white or light-coloured hair.

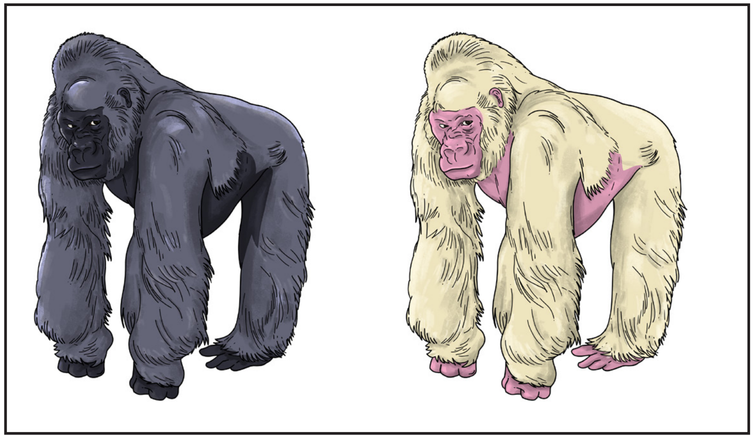
There are two major types of albinism in humans.

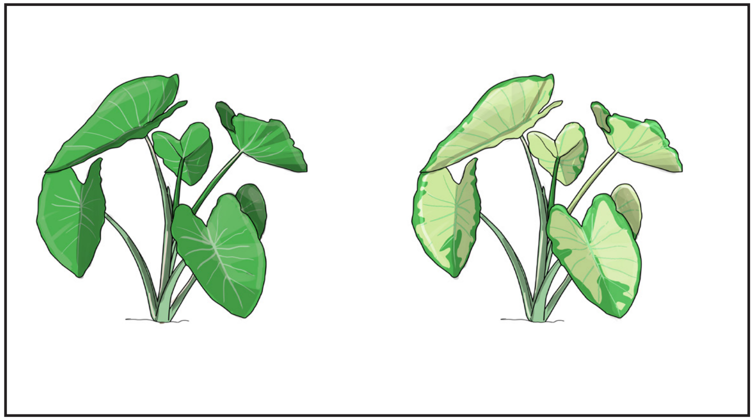
The most common type of albinism is oculocutaneous albinism (OCA), which is a group of rare disorders characterized by a reduction or complete lack of melanin pigment in the skin, hair and eyes.

The other major type is ocular albinism, which affects only the eyes.

Albinism is a condition inherited at birth that can affect anyone regardless of race, ethnicity or gender. People with albinism are born with the condition and it lasts throughout their life.

Albinism can be present also in animals and plants.





What causes albinism?

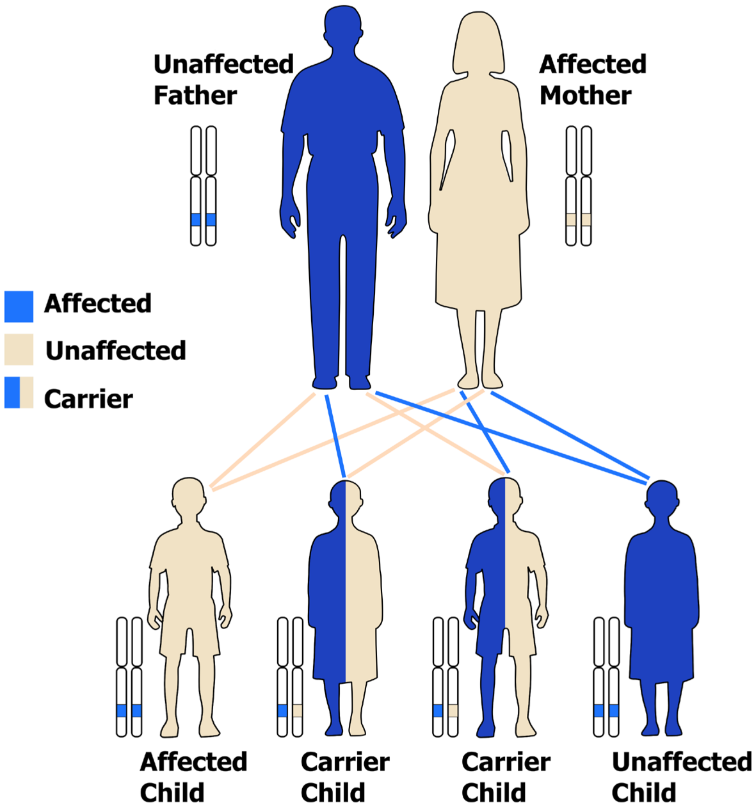
Albinism is caused by **genetic mutations.**

All persons carry genes. Genes carry information about the physical features or characteristics that are passed from parents to children. Genes determine whether a person will be tall or short, have curly or straight hair, black or white skin, blue or brown eyes, among others.

For one to inherit albinism, **both parents must be carriers of the rare (recessive) genes affecting the production of melanin and therefore the colouring of the skin, hair and eyes.**

Individuals who carry the genes causing albinism may not show any sign of albinism, yet their children can be born with albinism. About 1 in 70 people in the world are estimated to be albinism carriers with no visible signs.

REMEMBER: Albinism is not a disease or curse that can be passed on through physical contact. It is a condition.



Is albinism present everywhere?

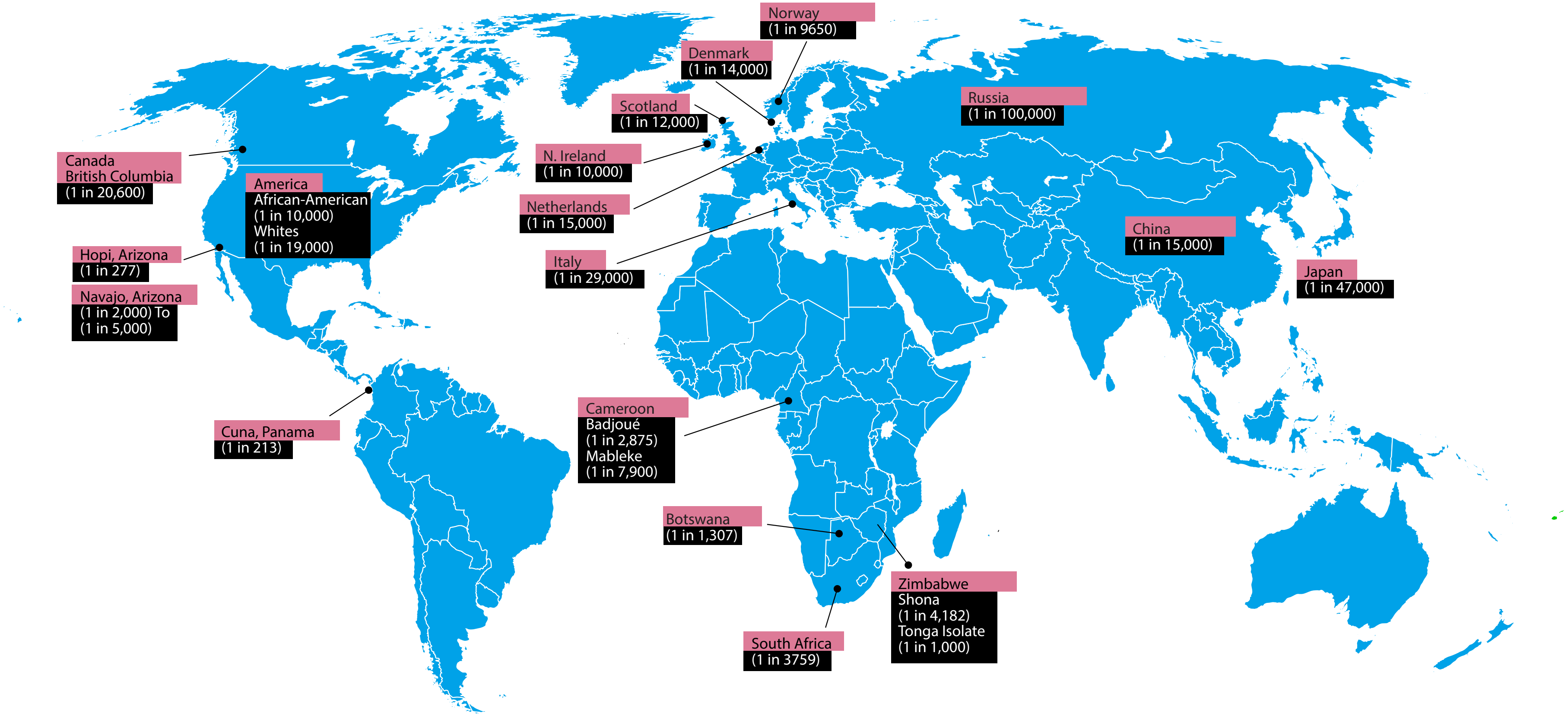
Albinism is present everywhere in the world, but its prevalence changes across the continents.

The World Health Organisation (WHO) estimates that the prevalence of albinism varies from 1 in 5,000 to 1 in 15,000 people in Sub-Saharan Africa. In Europe and North America the estimate is 1 in 20,000 people.

The occurrence in Africa is therefore far higher than the world wide average.

In South Africa the incidence of occurrence is about 1 in every 4,000 people.

In Nigeria the occurrence of albinism is about 1 in 5,000 people and in Tanzania the occurrence is 1 in 1,400 people. Exact data is not available for Uganda.


Norway
(1 in 9650)
Denmark
(1 in 14,000)
Scotland
(1 in 12,000)
Russia
(1 in 100,000)
Canada
British Columbia
(1 in 20,600)
N. Ireland
(1 in 10,000)
America
African-American
(1 in 10,000)
Whites
(1 in 19,000)
Netherlands
(1 in 15,000)
China
(1 in 15,000)
Hopi, Arizona
(1 in 277)
Italy
(1 in 29,000)
Japan
(1 in 47,000)
Navajo, Arizona
(1 in 2,000) To
(1 in 5,000)
Cameroon
Badjoué
(1 in 2,875)
Mableke
(1 in 7,900)
Cuna, Panama
(1 in 213)
Botswana
(1 in 1,307)
Zimbabwe
Shona
(1 in 4,182)
Tonga Isolate
(1 in 1,000)
South Africa
(1 in 3759)

FAQs addressing myths on persons with albinism

Are persons with albinism ghosts?	NO, persons with albinism are human beings just like you and me.
Do persons with albinism die or just disappear?	NO, persons with albinism do not disappear, they die just like any other person..
Do body parts of persons with albinism have curative powers?	NO, body organs of persons with albinism do not have any curative powers. They are normal just like every other human being.
Can persons with albinism cure HIV/AIDS?	NO, persons with albinism cannot cure HIV/ AIDS. An HIV positive individual will have to go to hospital for HIV/AIDS treatment and management.
Do persons with albinism bring good or bad luck?	NO, persons with albinism are human beings just like you and me.
Do persons with albinism bring good or bad luck?	NO, Persons with albinism are just like all of us, they neither bring good nor bad luck.
Can I get rich if I have sexual intercourse with a woman with albinism?	NO, you cannot get rich by having sex with a woman with albinism.

FAQs addressing myths on persons with albinism

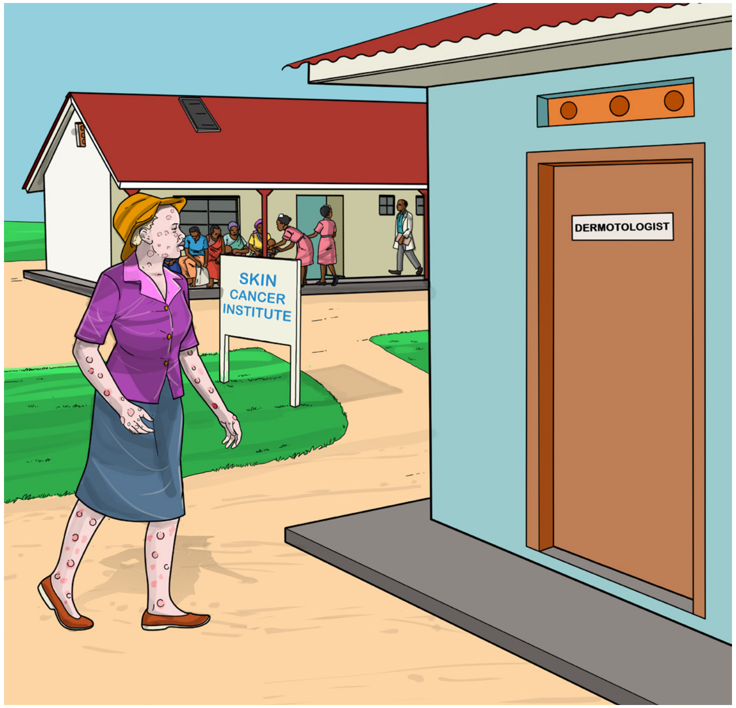
What is it like to have sexual intercourse with a man/woman with albinism?	Consensual sex with persons with albinism is no different from any sexual intercourse between two consenting adult individuals.
Do persons with albinism have super powers?	NO, persons with albinism do not have any super powers.
Do persons with albinism eat different food from the rest of us?	NO, persons with albinism eat foods common to the human race and may have dietary preferences just like everyone.
Can I get infected with albinism if I touch a person with albinism?	NO, albinism is not a disease. It is a non-contagious condition and cannot be acquired or transmitted through physical contact. It cannot be passed on from one person to another through contact and is not an air borne disease either.
Why did I get a child with albinism?	Because you and your spouse/partner are carriers of a recessive gene that causes albinism.
Do persons with albinism have red blood?	YES, persons with albinism have red blood just like all human beings.
Do persons with albinism emit light in the dark?	NO, persons with albinism are ordinary human beings and do not emit light.
Can you cut the hair of persons with albinism?	YES, persons with albinism can shave or cut their hair. But no one is allowed to cut their hair without their consent or for any other purpose.

II. HUMAN RIGHTS & ALBINISM

Health of persons with albinism

Basic information on health issues generally affecting Persons With Albinism

Most persons with albinism live normal life spans and have the same types of general medical problems as the rest of the population. **However, persons with albinism are more sensitive to sun exposure and often suffer from eye problems.**



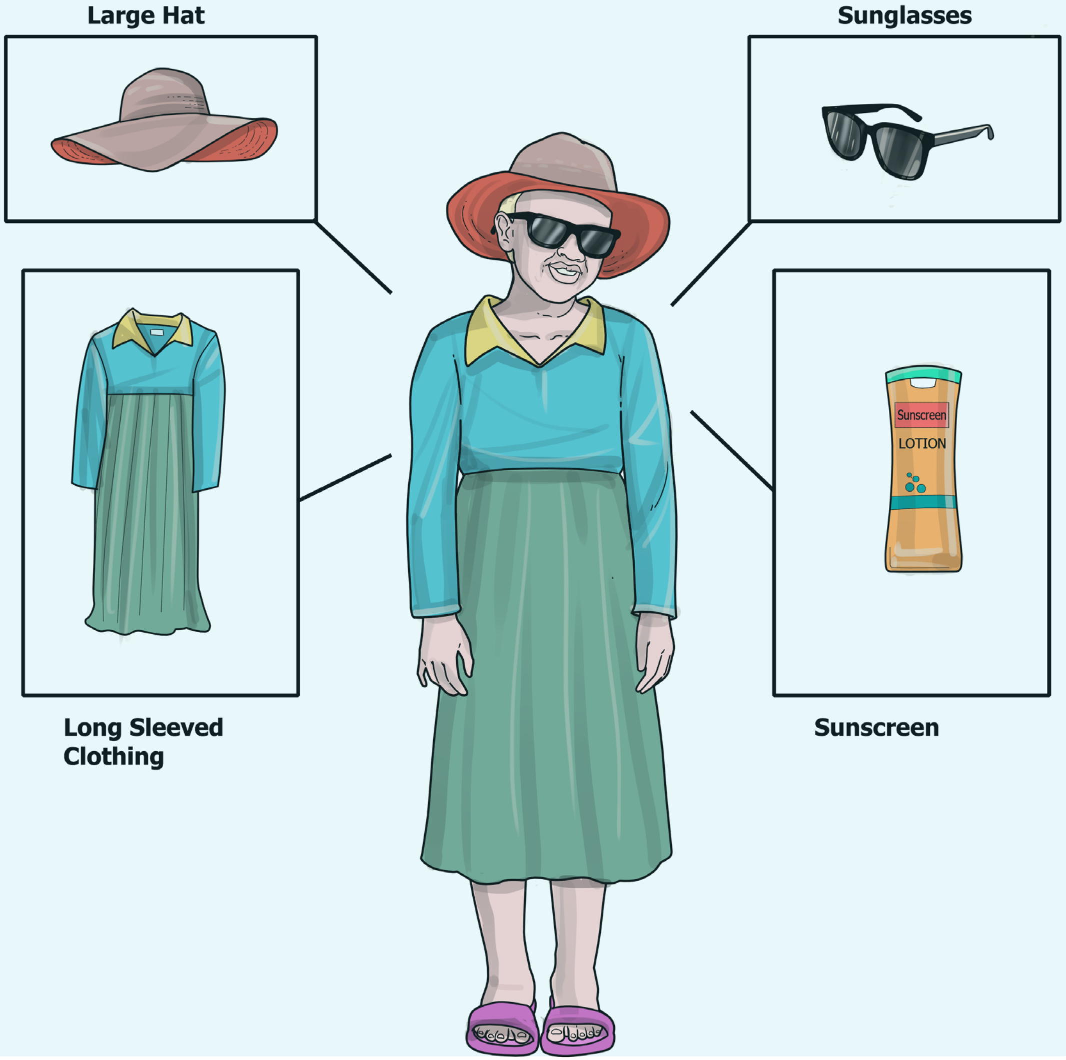
Persons with albinism are particularly vulnerable to **skin cancer** and need to be protected from exposure to the sun so as to prevent damage to their skin and eyes. For this reason, persons with albinism should avoid direct exposure to the sun during peak times (11am-4pm) and use hats, clothing that covers the entire body, sunglasses with UV protection and sun screen lotions.

In case of any skin disorders, lesions and/or blisters, persons with albinism should visit their nearest health center for assistance and possible skin cancer screening.

Albinism can also cause a variety of **visual impairments,** including involuntary back-and-forth movements of the eyes, inability to focus both eyes on a single point, extreme near/farsightedness, and sensitivity to light. The severity of symptoms varies and not all individuals with albinism will need accommodations. The vision of a person with albinism can range from normal to blindness. Eye glasses, corrective lenses and at times surgery can be performed to improve sight.

How can people with albinism protect their skin and eyes from the sun?

- By avoiding prolonged exposure to the sun especially during peak hours
- Regularly using appropriate and recommended sunscreen lotions
- Covering completely all parts of the body with clothing when exposed to the sun
- Wearing sunglasses with UV protection



Providing quality health care to persons with albinism

Currently, there is no national programme in place in Uganda to address medical concerns that may be unique to persons with albinism.

However, persons with albinism **do not need special or differentiated care for clinical management of common diseases,** for instance malaria.

They can receive the same treatment as any other person and it is their right to receive quality health care at all levels without discrimination.

Health workers do not need any specific qualification to treat a person with albinism; but their capacity can be built on what albinism is to be able to provide the appropriate services to them including psycho-social and counselling services. However, as for anyone else, they can be referred to **specialists for specific pathologies.**

With respect to maternal health, women with albinism or **those who give birth to children with albinism must not be stigmatized or discriminated on the basis of their condition.** Health workers must provide them with appropriate assistance as per clinical guidelines and procedures pertaining to health conditions that they present before them.

FAQs on Albinism and Health

Do all persons with albinism have disabilities?	Persons with albinism are recognized as persons with disabilities under national and international laws. However, not all persons with albinism experience disabilities. Disability refers to; "*substantial functional limitation of a person's daily life activities caused by physical, mental or sensory impairment and environment barriers, resulting in limited participation in society on equal basis with others*"[1].
Are persons with albinism blind?	NO, not all persons with albinism are totally blind. Most of them have vision problems and cannot see or read clearly unless subjects or materials are brought close to their eyes. The condition is referred to as short-sightedness.
Do all persons with albinism need eyeglasses?	NO, not all persons with albinism need eyeglasses. Shortsightedness is as a result of low melanin in persons with albinism. Melanin is involved in the biological development of the human eye and sight system. So those with the least pigment will have the poorest vision and will need eyeglasses while those with some pigment may read big font without glasses.
Can I get skin diseases if I touch a person with albinism?	No, you cannot.
Why do persons with albinism always have large brimmed hats?	The large brimmed hats protect their skin from the sun so that they do not develop blisters that may eventually lead to skin cancer. Hats also protect their eyes from direct sun light.
Why do persons with albinism use sunglasses?	They use sunglasses to protect their sensitive eyes from the sun.

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[1] Section 1 of the Ugandan Persons with Disabilities Act, 2020.

FAQs on Albinism and Health

Why should persons with albinism wear clothes that cover their entire body?	It is recommended that they wear clothing that does not expose any part of their body to the sun because their skin lacks melanin and needs to be protected from exposure to direct sunlight. If exposed to direct sunlight, their skin may burn and develop blisters that may lead to skin cancer.
What are sunscreen lotions?	These are special skin protection lotions commonly referred to as sunscreens. Persons with albinism need to use them to protect their skin from developing blisters due to exposure to the sun.
Are sunscreen lotions cosmetics?	NO, sunscreen lotions are an essential lotion for persons with albinism to help protect their skin from sun burn. It is an essential medicine for persons with albinism.
What causes the black spots on the body of persons with albinism?	This is due to the lack of protective melanin pigment in their skin. Person with albinism are extremely sensitive to the damaging ultraviolent rays of the sun, which will cause burning and ageing of the skin. They may have blistered dark and hard skin with skin lesions which can develop into skin cancer.
Do persons with albinism bathe in warm water?	YES, they can bathe in warm water like anyone else.
Do persons with albinism really see well in the dark?	No, persons with albinism cannot see in the dark. However, with appropriate light and eyeglasses they can see well in the dark, just like you and me.
Are children with albinism subject to immunization?	YES, children with albinism are subject to immunisation and any other recommended inoculations for infants and children.

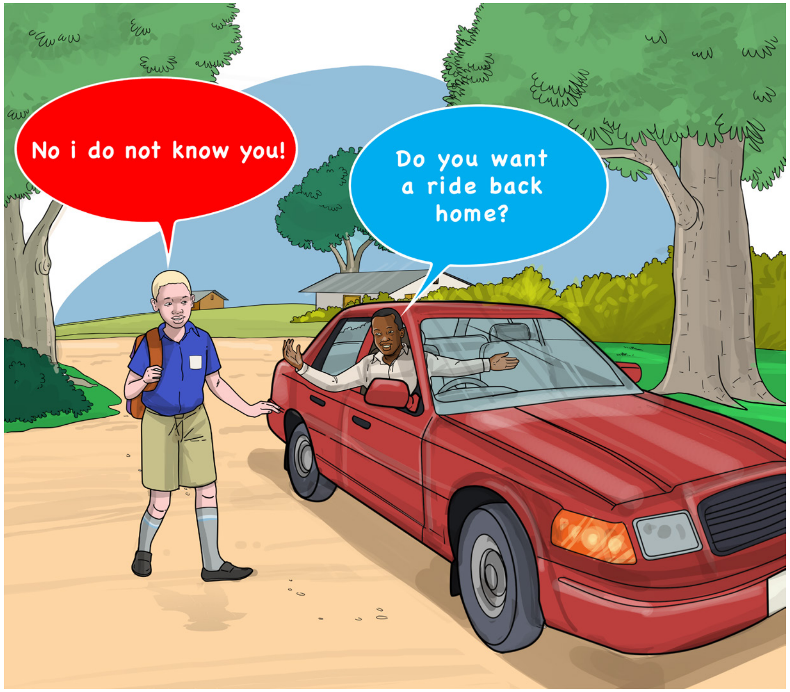
Education and Employment of Persons with Albinism

Basic information on access to education

Children with albinism have the same right as everyone else to quality education and can be very successful students if supported with necessary equipment or aids.

Parents, teachers and communities at large need to support children with albinism because they can excel at school, university and any other learning institution.

In Uganda, children with albinism face several **challenges accessing and remaining in schools.** These challenges first arise at the household level where some parents choose not to send these children to school because they are considered having no future, or they fear for their safety or, sometimes as abandoned mothers, they cannot afford school fees.



Going to school, especially in rural areas or when children have to walk long distances to reach the school, can expose children with albinism to the ***risk of being kidnapped or attacked.*** Children are particularly at risk in those communities that erroneously believe that their body parts have magical powers. As a result, many parents fear to send their children to school and prefer to keep them safe at home.

For those who manage to reach school safely other challenges exist. Although not every child with albinism has a visual impairment, many experience **low vision.**

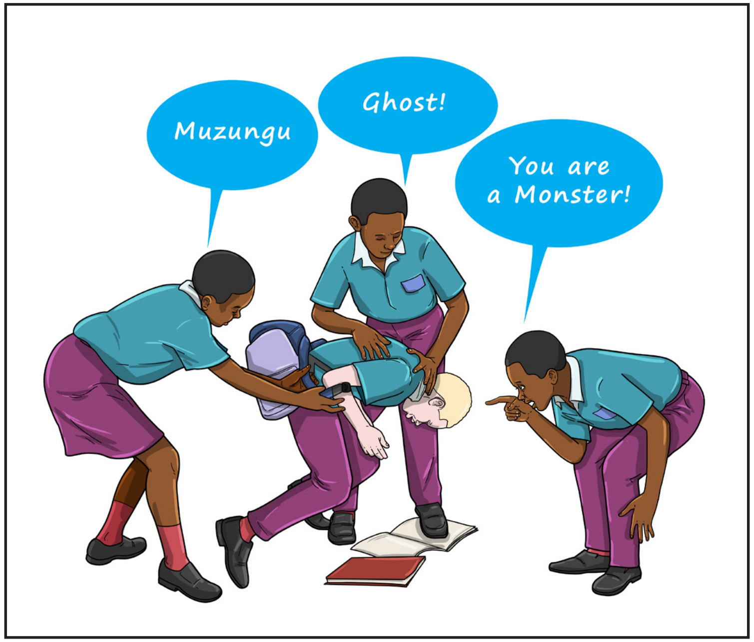
This causes ***difficulties in reading small fonts in textbooks and blackboards***.

Due to lack of knowledge of the visual challenges, some parents and teachers even believe that children with albinism are not able to perform well in school. In order to perform well, children with albinism with sight problems need **to sit in front and teachers should write in large font size**.

Teachers should also allow students with albinism extra time to read texts and answer questions, particularly during exams.

Some schools do not allow students to put on ***long-sleeved school uniforms*** or to skip activities carried out outdoor during peak hours. This exposes students with albinism to the sun's rays and put them at risk of developing skin cancer.

Some parents and guardians of learners with albinism often do not have the knowledge or resources to support their children's access to education, for instance they may not afford learning aids.



Students with albinism often suffer from ***bullying*** by their peers without adequate protection from teachers or school management and decide to drop off. Girls in particular can suffer from sexual harassment.

FAQs on Education

Can children with albinism perform well in school?	YES, they can perform well and reach university. They just need to be supported and some adjustments are needed to accommodate their learning and to ensure they are safe and comfortable at school like any other student.
Why are there so many children with albinism who are not in school?	Many children with albinism are not in school because of the many obstacles they face to access education, including difficulties in reading and bullying, societal stigma and discrimination, inability to afford school fees and the necessary equipment to accommodate their learning, and fear of being kidnapped or attacked on their way to school also contribute.
Why should students with albinism sit in front of the class?	Learners with albinism are shortsighted, which means that they cannot see well from far. They can only see things that are close to their eyes. They need to sit in front of the class so that they can see the teacher's instruction board (black board) clearly.
Why should learners with albinism not wear the regular school uniform like others?	Learners with albinism must wear long sleeved school uniforms and round brimmed hats to protect their skin from the sun.
Can children with albinism play sports?	YES, children with albinism can play any sport. School authorities, parents and guardians need to ensure that they have the required protective gear and are not exposed to the sun.

FAQs on Education	
How do I know if my child with albinism/ students with albinism needs visual aid?	Take your child for medical check up to ascertain if they are visually impaired or not.
What if my child with albinism cannot see well?	If you are a parent or guardian to a learner with albinism who cannot see well, engage their teacher so that he/she is allowed to sit in front of the class or closer to visual learning aids and teacher's instruction board (blackboard). This will enable them to see clearly and understand the teacher's instructions.
How can I ensure that my students with albinism are well-accepted by their peers?	By engaging the teachers and school management of the child to make sure the child will comfortably stay in school and enjoy learning. Encourage the school and teachers to sensitize the peers of the children at school about albinism.
Are children with albinism entitled to education?	YES, children with albinism are like any other child. If given proper support by school authorities, teachers, parents and guardians, they can excel in education and extra-curricular activities. Many children with albinism successfully complete their education and become productive members of society.
Can my child pursue any career of his/her choice?	YES, your child can pursue any career of their choice. Children with albinism need support to realize their full potential. Parents and guardians of children with albinism should enroll their children in school and support them throughout their schooling.

Persons with albinism and employment

Persons with albinism experience **additional challenges in accessing employment.** These challenges can be linked to two main reasons: lack of skills due to limited education and erroneous perceptions regarding their capacity to work. This results in additional discrimination and stigma.

Many persons with albinism face challenges accessing quality education. Therefore many have **limited chances of acquiring professional skills** that would allow them to get a good job to support themselves and their families.

Persons with albinism face **negative attitudes from employers** because of their condition. Many employers believe that persons with albinism cannot perform well in their jobs because of their condition and related disabilities. This is wrong. **Persons with albinism can perform well in any job, both intellectual and manual. They only need a conducive work environment responsive to their needs.**

FAQs on Employment	
Can persons with albinism do any type of work?	YES, persons with albinism can do any work just like anybody else. They only need adequate accommodation, such as protection from direct exposure to the sun and appropriate vision magnification. Not all people with albinism will need accommodations to perform their jobs and many others may only need a few accommodations.
Will persons with albinism scare my clients?	NO, persons with albinism will not scare your clients. They are human beings just like you and I.
How can I contribute to raise awareness among my friends, clients?	By letting them know that a part from the challenges they have of the skin and visual impairment, Persons with albinism are just like you and me.
Are persons with albinism weak?	NO, persons with albinism are not weak. They are strong and healthy people.
Can persons with albinism work at every time of the day?	YES, they can work at any time of the day, as long as they are not exposed to the sun's ultra violet rays when it is hot. Also women on night shifts without proper transport to get to work may be at risk or exposed to attacks.
Can they do manual work?	YES, persons with albinism can do any manual work like any other person.

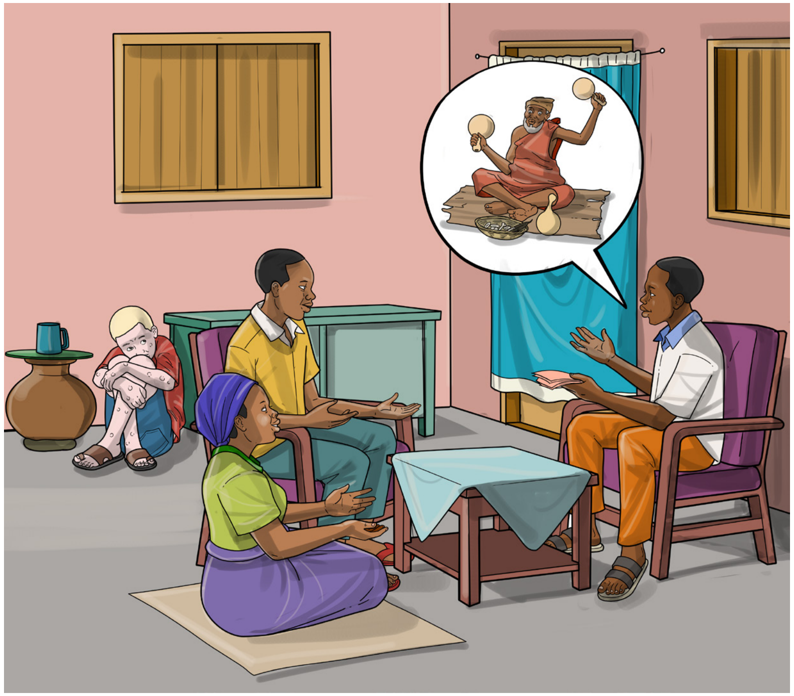
Security of persons with albinism

False beliefs and harmful myths around albinism have led to attacks against, kidnappings and killings of persons with albinism, including women and children.

In some communities, especially in Sub-Saharan Africa, the security and lives of persons with albinism are at constant risk. The false belief that the body parts of persons with albinism possess magical powers that can be used to gain wealth and prosperity or bring good luck are some of the reasons behind the attacks. **Ritual killings** are perpetrated by using body organs for witchcraft rituals, and body parts of children are considered especially valuable. Women and girls with albinism also experience **sexual violence** based on the false belief that sexual intercourse with a woman with albinism cures HIV Aids.

These attacks are often committed with impunity and with the involvement of a family member in exchange of large amounts of money.

In Uganda, relatively few attacks have been reported, but this does not mean that risks to security do not exist. On the contrary, many cases have been reported and many more go underreported, including cases of bullying and sexual violence.



What can persons with albinism do to protect themselves?

- Persons with albinism should avoid moving alone, especially at night.
- Parents and guardians should accompany their children with albinism to school or make sure that they do not walk alone.
- Parents and guardians should engage with school authorities and teachers to ensure that they are aware of risks and ensure safety of their children at school.
- Parents and guardians should talk to their children and make sure that they are aware of the risks and how to avoid them.
- If persons with albinism are to travel, they should communicate their movements to relatives or friends before leaving and upon arrival at their final destination. Whilst in travel, they should endeavor to keep relatives and friends informed of any challenges or potential threats to their safety.

Who to report to in case of attacks?

Report all attacks, violence, kidnappings and other forms of abuse directed at persons with albinism to the nearest LC.1 or police station around your area of residence or NGOs working on albinism in your area.

Women and girls with albinism

Women and girls with albinism are particularly vulnerable as they are exposed to intersecting and multiple forms of discrimination because of their gender and condition.

Specific challenges faced by women and girls with albinism include sexual violence, forced early marriages, social blame and exclusion in relationships, poverty and health risks.

Sexual violence and discrimination

Women and girls with albinism are at high risk of becoming victims of sexual violence. This is due to a false belief that sexual intercourse with a woman with albinism can cure HIV/AIDS or

Some men are interested in satisfying sexual mysticism and curiosity around having sexual intercourse with persons with albinism. This exposes women with albinism to violence and sexually transmitted infections, unwanted pregnancies and societal exclusion on moral grounds.

Many women with albinism in Uganda are single mothers, or have faced domestic violence, abandonment, mental and emotional abuse, and discrimination in marriage with families of the husband encouraging them to find another wife.

Women, and therefore women with albinism, often face various barriers to access justice and crimes against them often remain unpunished.

Blame and Abandonment after having a child with albinism

In Uganda, the mother of a child with albinism is often blamed for causing the pale colouring of the child. As most people do not know that albinism is a genetic condition transferred by both parents, the woman is often accused of being unfaithful in her marriage or being cursed. Consequently, mothers are often abandoned by their husbands.

Poverty

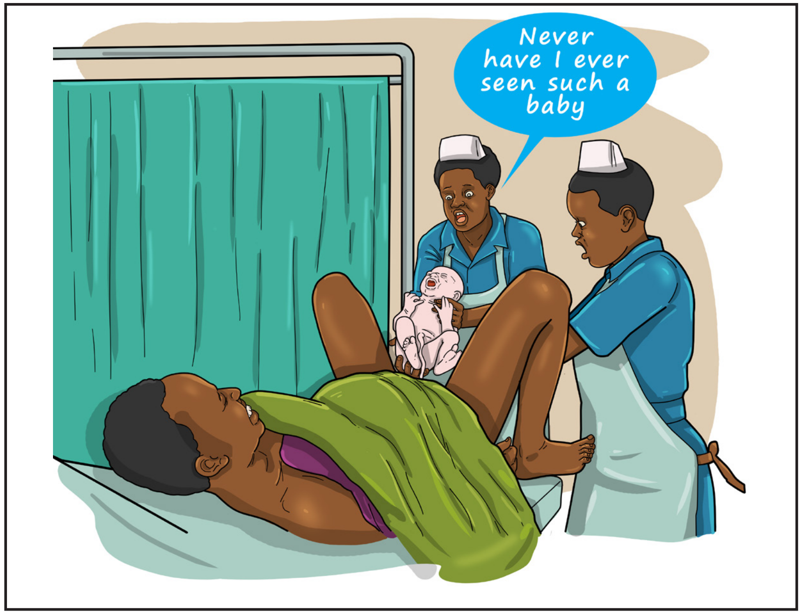
Social rejection and abandonment of both women with albinism and women giving birth to children with albinism places undue economic and emotional strain on women. The rejection of both the mother and child exposes them to poverty and isolation, which further increases their vulnerability including to attacks. The child with albinism of a single mother is likely to be exposed to further poverty because he is often unable to access education.

Due to a general lack of sufficient education of girls with albinism, women with albinism are more likely to work in the informal sector with lower-paying wages/salaries, and face additional barriers in accessing formal employment.

However, women with albinism can set up their small businesses in communities and should be supported by their communities.

Maternal health risks

Midwives play a crucial role in helping deliver life to the world. However, many midwives lack knowledge about albinism and believe in traditional myths and stereotypes. In some cases, mothers with albinism and of a child with albinism have not received adequate health care. To the extent that some mothers with albinism or of a child with albinism have been denied assistance from midwives claiming not to know how to handle those children.



III WHAT CAN EVERYONE DO TO IMPROVE LIVES OF PERSONS WITH ALBINISM?

There are many things that can be done to improve the lives of persons with albinism, including women and children. Below some of the most important dos and don'ts for parents, teachers, health workers, local authorities and community leaders, and police.

PARENTS

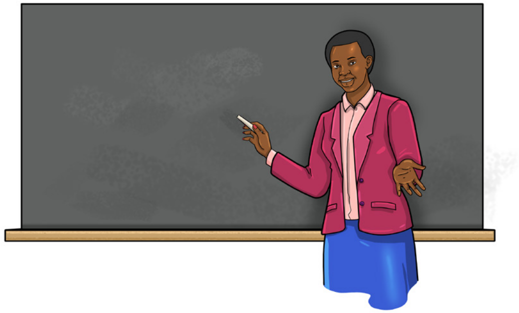
Do

- Support the early childhood development of every child with albinism
- Ensure that children with albinism are enrolled and kept in school so that they grow up like any other child
- Sensitize family members and community against negative societal attitudes towards albinism
- Protect children from sun exposure
- Make them aware of societal risks related to their condition
- Check if a child with albinism has visual impairment.

Don't

- Do not discriminate against a child with albinism and treat all children equally
- Do not let children with albinism go to school unaccompanied
- Do not believe that a child with albinism is a curse or brings bad luck.

TEACHERS AND SCHOOL AUTHORITIES



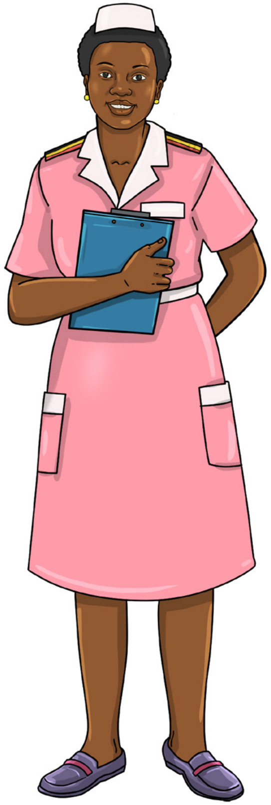
Do

- Train teachers on the needs of learners with albinism so that they can be able to provide appropriate and adequate support
- Assess the individual needs of each learner with albinism, including their sight
- Allow learners with low vision to hold books and papers closer to their eyes while reading and writing and allow extra time to complete exams as appropriate
- Arrange outdoor activities early in the morning or late afternoon to avoid the midafternoon sun
- Help learners with albinism to have a sense of belonging to the wider community of learners by engaging them in all activities
- Encourage them to fully explore their talents and potential, and thus develop important life skills such as self-esteem
- Sensitize other children about albinism to avoid naming and bullying.
- Take appropriate pro-active steps to dissuade would be bullies from abusing learners with albinism
- Wherever possible, school authorities should provide learning aids that support learners with albinism, for example, provide monocular telescopes
- Ensure safety measures against violence or ritual attacks i.e. ensuring learner does not walk home alone; ensuring safety of the school compound etc

Don’t

- Do not make children with albinism to sit far from the instruction board (blackboard)
- Do not force children with albinism to be exposed to direct sunlight while engaged in learning and extra-curricular activities
- Do not use derogatory titles or names when referring to learners with albinism.

HEALTH WORKERS



DO

- Treat all patients the same including persons with albinism
- Take all the necessary steps to ensure quality care to patients with albinism, especially on preventable diseases such as malaria and typhoid
- Refer persons with albinism to skin specialists in case they note signs of skin lesions and ophthalmologist to be provided with glasses or visual aids.
- Request training on how to deal with health challenges of persons with albinism like how to offer advice, guidance, counselling or psycho-social support if needed.

DON'T

- Do not discriminate against patients with albinism
- Do not refuse to treat a patient with albinism
- Do not let patients with albinism queue directly under the sun while they wait for their turn to be assisted.

EMPLOYERS

DO

- Support persons with albinism by creating conducive working conditions and environments, for example by providing protective gear and ensuring that work stations are sufficiently lit
- Have a recruitment policy that encourages applications from people with disabilities and deliberate equal opportunities policies.

DON'T

- Do not discriminate against persons with albinism when recruiting employees
- Do not expose employees with albinism to direct sunlight at their workstations without protective gear

COMMUNITIES AND LOCAL AUTHORITIES

DO

- Refrain from disseminating myths and false beliefs against persons with albinism
- Be supportive and treat persons with albinism like a other person
- Report any cases of discrimination or attacks on pers with albinism to the local authorities
- Sensitize community members on albinism Including faith-based actors to speak strongly against the myt and errors that are the root causes of ritual attacks

DON’T

- Do not discriminate against and stigmatize persons albinism
- Do not enable or conceal abuses and human rights violations against persons with albinism
- Do not exclude persons with albinism from any community activities.

POLICE

DO

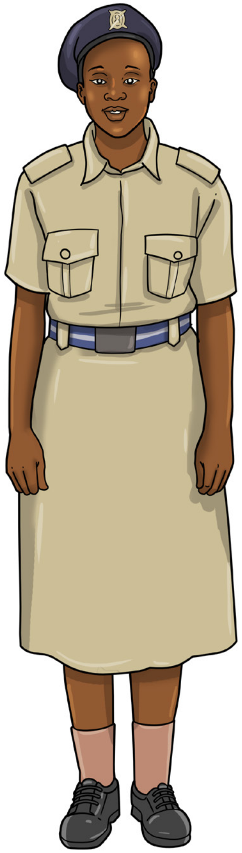
- Investigate all cases brought to their attention related to crimes and human rights violations against persons with albinism and forward the file to the Office of the Director of public prosecutions (ODPP) for prosecution when appropriate

- Carry out advocacy through community policing to prevent attacks and other human rights violations on persons with albinism in communities.

- Make sure that police officers have knowledge about threats to the security of persons with albinism.

DON'T

- Do not ignore or take lightly case reports from persons with albinism or allegations of human rights violations against persons with albinism, including ritual killings, kidnappings and sexual violence.



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