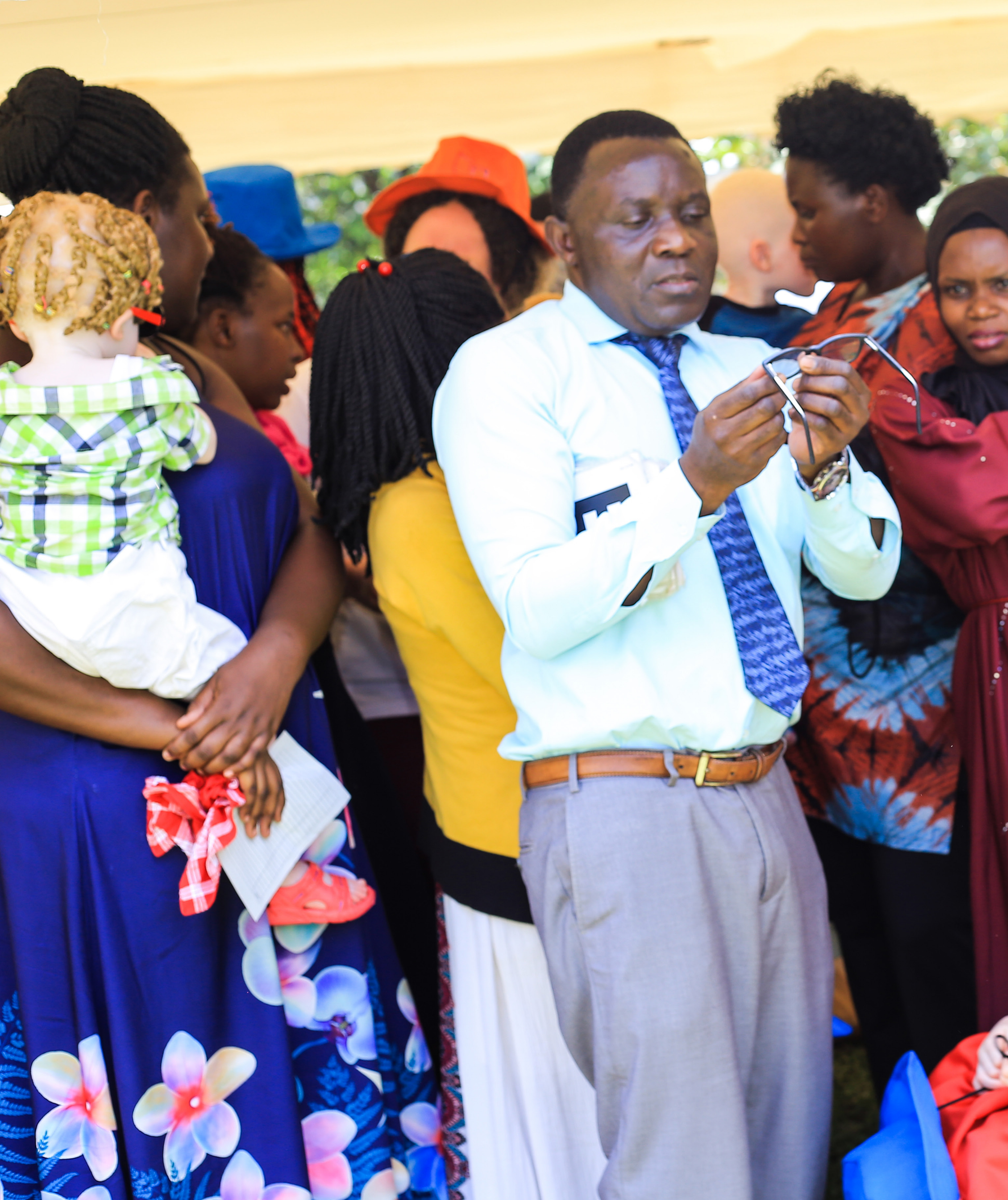
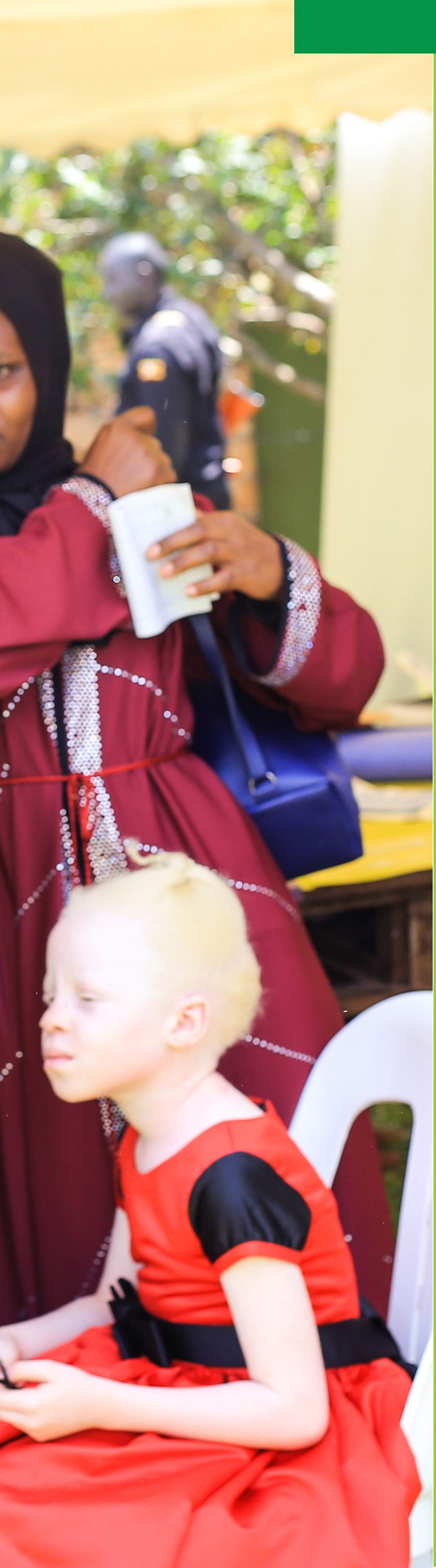
Albinism Umbrella

BEYOND THIS SKIN

ALBINISM HEALTH AWARENESS HANDBOOK





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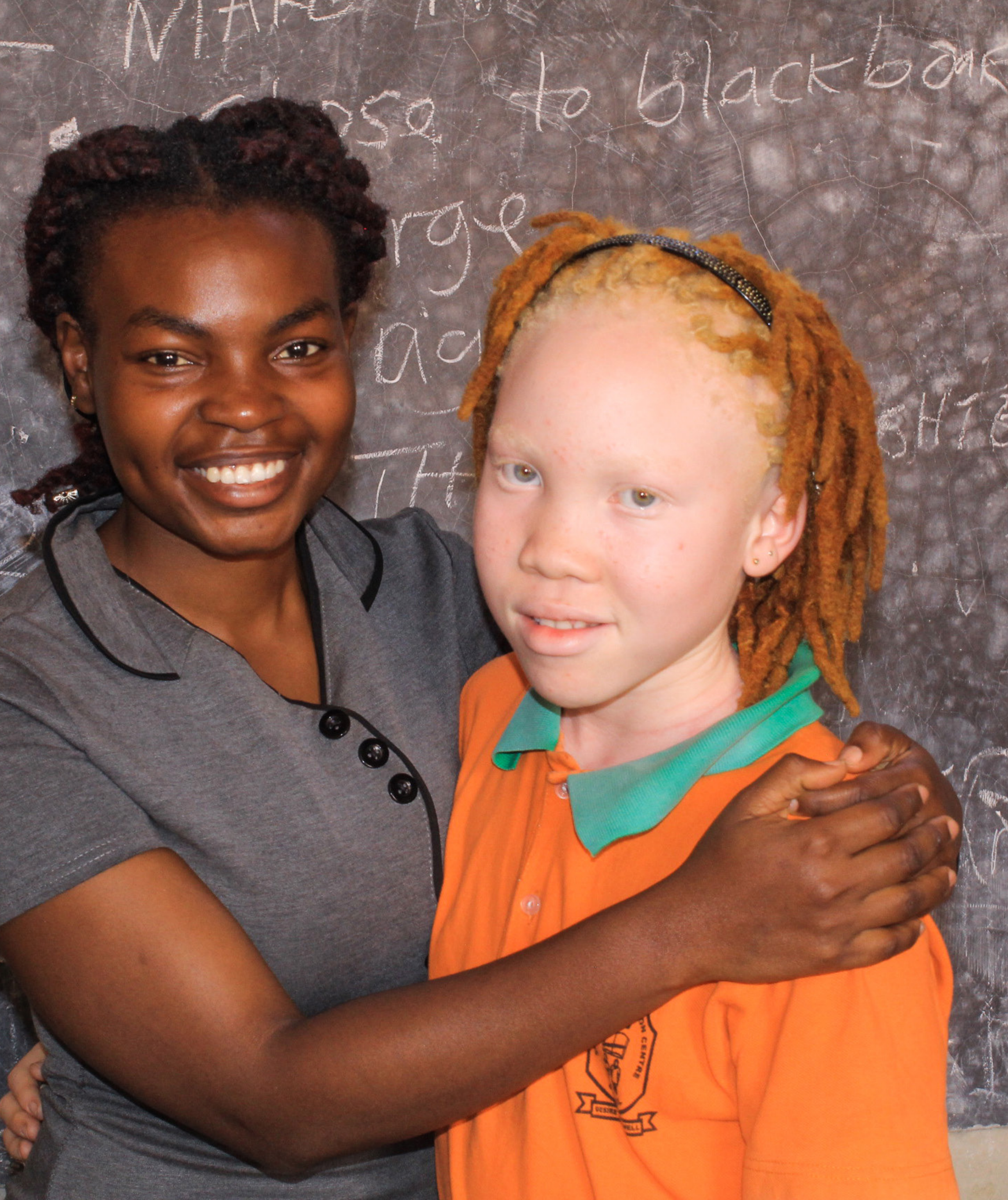
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1.0 INTRODUCTION

Albinism is a widely unknown condition and there are widespread myths and misconceptions about 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. Albinism can be found in all living things that is plants, animals, and people from all over the world.

The handbook aims to raise awareness of albinism, highlighting ongoing challenges and addressing myths and misconceptions around albinism that affect the enjoyment of their human rights. By raising awareness and understanding albinism, we can promote inclusivity, reduce stigma, and improve the overall health and well-being of persons with albinism.

1.1 Definition

Albinism is an inherited genetic condition that reduces the amount of melanin pigment formed in the skin, hair, and/or eyes. Albinism occurs in all racial and ethnic groups throughout the world.

1.2 Types of Albinism

The major two types of albinism are;

i. Oculocutaneous albinism (OCA)

OCA majorly affects the skin, hair, and eyes.

ii. Ocular albinism

Ocular albinism (OA), which is much less common, involves only the eyes, while skin and hair may appear similar or slightly lighter than that of other family members. This type of albinism only affects the eyes. People with this type have coloring in the hair, skin, and eye coloring, but have no coloring in the retina (the back of the eye)

1.3 Magnitude

Albinism is a rare genetic condition, and its prevalence varies across different populations and regions. The global prevalence of albinism is estimated to be approximately 1 in 20,000 to 1 in 40,000 persons.

According to recent research by Kromberg JGR 2023, et al, the albinism prevalence in Africa is 1: 4,000-7,000 rising from the previous 1: 17,000. According to the National Organization for Albinism and Hypopigmentation, about 1 in 18,000 to 20,000 people in the United States have a form of albinism.

In Uganda, DHS, Census, and Surveys put Persons with albinism in the same category as Persons with disabilities hence the actual prevalence of 20,000.

The Uganda Bureau of Statistics Census Report (UBOS 2016) indicated that 12.4% of the Ugandan population lives with some form of disability implying that approximately 4.5 million Ugandans are persons with disability.

Regional variations show that regions with a higher prevalence of albinism include parts of Sub-Saharan Africa, where the condition is estimated to occur in as many as 1 in 1,000 to 1 in 5,000.

1.4 Genesis about albinism.

- The albinism gene is recessive, someone can carry the gene without having albinism and it can be passed on to the child by both parents i.e. both parents must carry the albinism gene in order to have a child with albinism.
- Parents themselves do not need to have albinism to be carriers; they have one functional copy of the gene, so they produce pigment, and one altered, non-functional copy.
- If both parents carry the albinism gene the probability of having a child with albinism is 25% (1 in 4) in each pregnancy.
- If a baby inherits a non-functional copy of the gene from both parents, they will not produce melanin pigment and will therefore have albinism.

2.0 HEALTH CHALLENGES FACED BY PERSONS WITH ALBINISM

In this section, we will explore the vision challenges commonly associated with albinism and discuss ways and resources for managing them effectively.

2.1. Eyes (visual)

Persons with albinism face the following visual challenge. Iris- photophobia, optic nerve- refractive error- macula not formed well and have poor focus, Nystagmus or dancing eyes, color vision not developed, squint, poor head posture, depth perception.

a) Low Vision Aids and Assistive Technology

To help persons with albinism overcome their vision challenges, a variety of low-vision aids and assistive technologies are available. The available options may include,

Magnifiers, large-print materials, high-contrast materials, prismatic glasses, telescopic glasses, screen readers, and text-to-speech software.

b) Eye Care and Management

Proper eye care and management are essential for persons with albinism to maintain their eye health and maximize their vision potential.

i. Regular Eye Examinations.

Routine eye examination by a qualified eye care professional is essential for monitoring vision and detecting and addressing any eye health issues promptly.

ii. Low Vision Specialists.

Low vision specialists can provide comprehensive assessments and recommend adaptive strategies and devices tailored to an individual's specific needs.

iii. Vision Therapy.

Vision therapy exercises can help improve eye coordination, reduce nystagmus, and enhance visual skills.

iv. Sun Protection.

Protecting the eyes from sunlight is crucial to prevent photophobia and reduce the risk of eye damage. This includes wearing sunglasses with UV protection and wide-brimmed hats.

v. Education and Support.

Schools and educational institutions should be informed about a student's visual challenges to provide appropriate accommodations, such as large-print text books or assistive technology.

2.2 Skin and Sun Protection

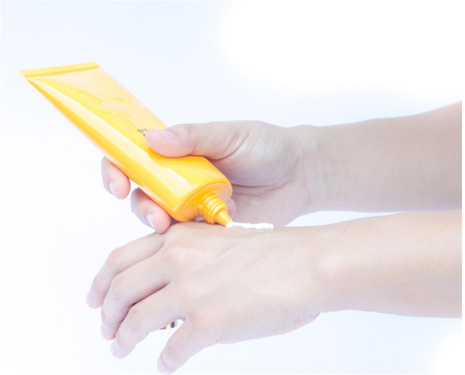
Persons with albinism have light-colored skin that increases the risk of sunburn. Due to the high risk of sunburn, persons with albinism have an increased risk of skin cancer. Skin cancer in persons with albinism is not merely a health issue; it is rooted in social disconnection, stigma, and discrimination as a result of ignorance about the condition.

a) Skin care and management

Sun protection measures include.

i. Sunscreen.

- Daily application of broad-spectrum sunscreen with SPF 30 or higher is crucial, even on cloudy days, persons with albinism ought to apply sunscreen every two hours especially when outdoors.



- Use sunscreen lip balms to protect the lips.

ii. **Protective Clothing.**

- Wear long-sleeved shirts, long pants, wide-brimmed hats, and sunglasses with UV protection.
- Seek shade whenever possible, especially during peak sunlight hours between midday and three in the afternoon.

iii. **Sun-Protective Gear.**

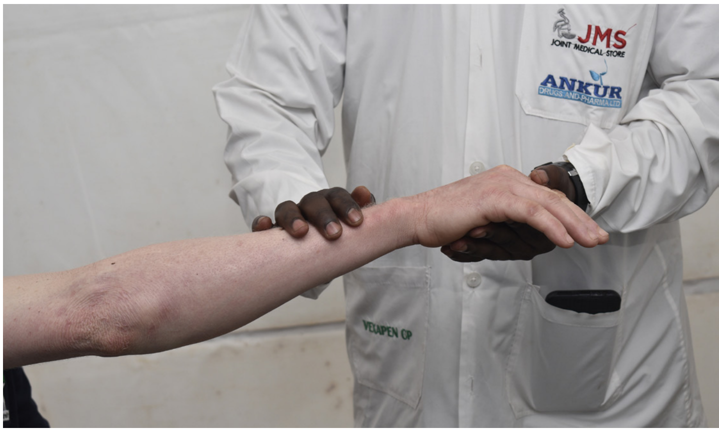
Consider using sun-protective clothing and swimwear designed with UPF (Ultraviolet Protection Factor) ratings for added sun safety.

iv. **Sun Safety Education.**

- Educate yourself and others about the importance of sun safety and the increased risk of skin cancer for persons with albinism.
- Promote sun safety awareness in schools, communities, and workplace.

v. **Skin Cancer Screening:**

Persons with albinism should have regular skin cancer screenings performed by a dermatologist.



Treatments for Skin Conditions:

Consult a dermatologist for the management of common skin conditions like eczema, which can be more prevalent in persons with albinism due to sensitive skin.

Scar Management:

Skin lesions, blisters, or burns can lead to scarring in persons with albinism thus scar management options can be discussed with a healthcare professional, including topical treatments and laser therapy.

3.0 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. Below are some of the most important dos and don'ts for parents, teachers, health workers, local authorities and community leaders, and police.

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 notice signs of skin lesions and ophthalmologist to be provided with glasses or visual aids.
- Request training on how to deal with the health challenges of persons with albinism like how to offer advice, guidance, counseling or psychosocial 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.

Medical training institutions

DO:

- Train learners using proper language on genetics made up of albinism.
- Promote the development of sensitivity and empathy in nursing students through scenarios, role-playing, and real-life stories. This can help students better relate to their experiences
- Offer continuing education opportunities for practicing nurses and healthcare professionals to update their knowledge and skills related to albinism and the evolving field of healthcare.

DON'T:

- Do not use language that promotes discrimination
- Deeper explanation of medical terms about the different conditions of human beings

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.

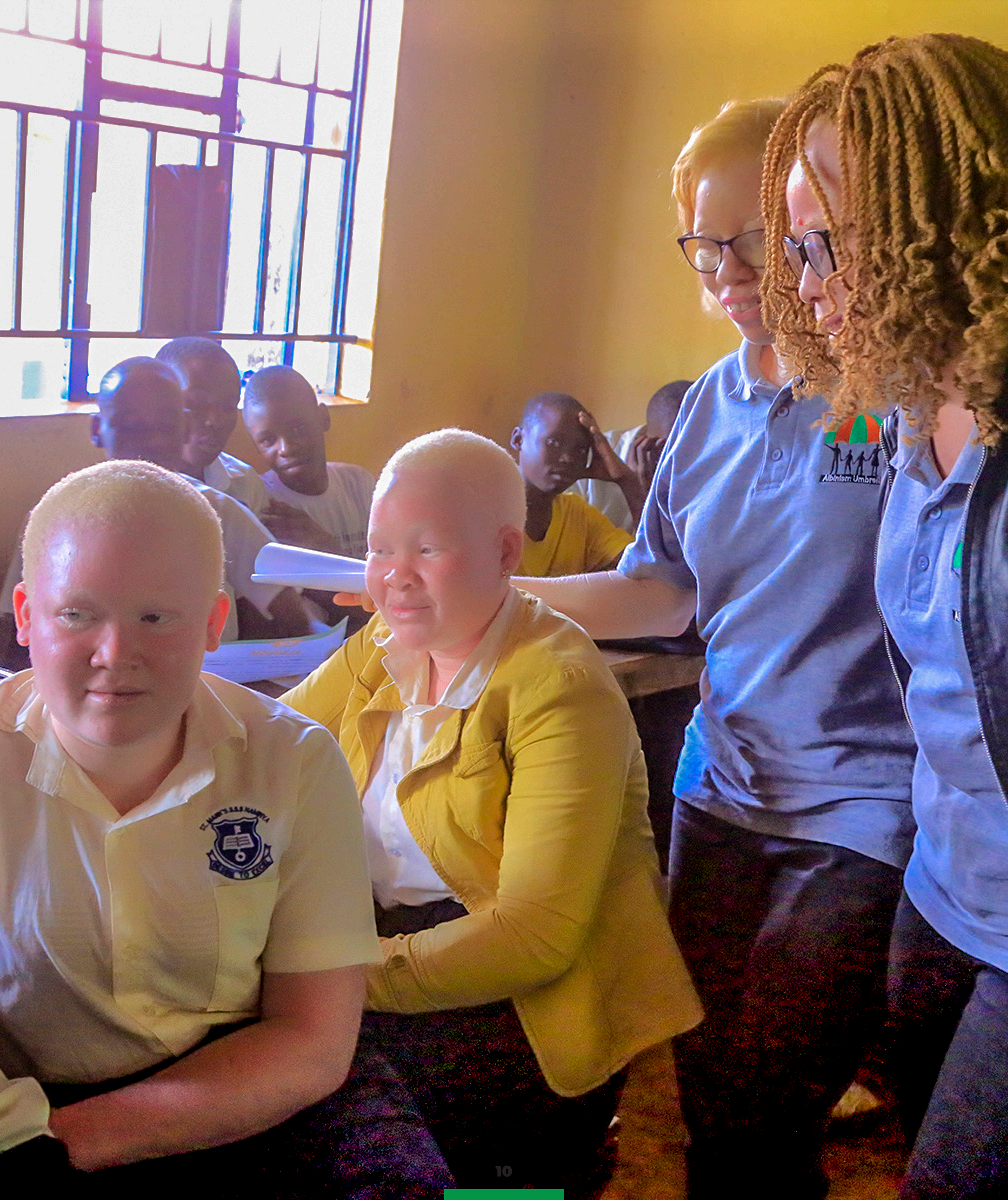
TEACHERS AND SCHOOL AUTHORITIES

DO:

- Train teachers on the needs of learners with albinism so that they can be able to provide appropriate and adequate support and 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 mid-afternoon 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 proactive steps to deter 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 the safety of the school compound etc.

DON’T:

- Do not make children with albinism sit far from the instruction board (chalkboard).
- Do not force children with albinism to be exposed to direct sunlight while engaged in learning and extracurricular activities.
- Do not use derogatory titles or names when referring to learners with albinism.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4.0 FAQS ON ALBINISM AND HEALTH

1. **Can persons with albinism live a normal life?**

   Persons with albinism can live normal, healthy lives. However, you should limit the amount of time you spend outdoors due to sun exposure. Some persons with albinism deal with social isolation due to the stigma of the condition. You should talk to your family, friends, and therapists for support with your condition.

2. **When should I see my healthcare provider?**

   If you develop any symptoms that cause physical discomfort, visit an eye specialist regularly. Also, go for medical attention if you notice any new skin changes.

3. **Can persons with albinism cure HIV/AIDS?**

   NO, persons with albinism cannot cure HIV/AIDS. An HIV-positive person will have to go to a hospital for HIV/AIDS treatment and management.

4. **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.

5. **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.

6. **Is having a person with albinism a result of being impregnated by a white man, or that the devil replaced the child with a person with albinism?**

   No, it is not true

7. Do persons with albinism have red blood?

YES, persons with albinism have red blood just like all human beings.

8. Is Albinism contagious?

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 by physical contact nor is it an airborne disease.

9. Why did I get a child with albinism?

Because you and your spouse/partner are carriers of a recessive gene that causes albinism.

10. Can albinism be prevented?

NO, Albinism is an inherited condition. People with a family history of albinism should consider genetic counseling.

11. What is the treatment for albinism?

There is no cure for albinism. You must manage the condition by being vigilant about sun protection.

12. Are children with albinism subject to immunization?

YES, Children with albinism are subject to immunization.

13. Do all persons with albinism have disabilities?

Yes, persons with albinism are recognized as persons with disabilities under national and international laws. 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 an equal basis with others"

14. Are persons with albinism blind?

NO, not all persons with albinism are 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.

15. Do all persons with albinism need eyeglasses?

NO, not all persons with albinism need eyeglasses. Shortsightedness is 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.

16. What are sunscreen lotions?

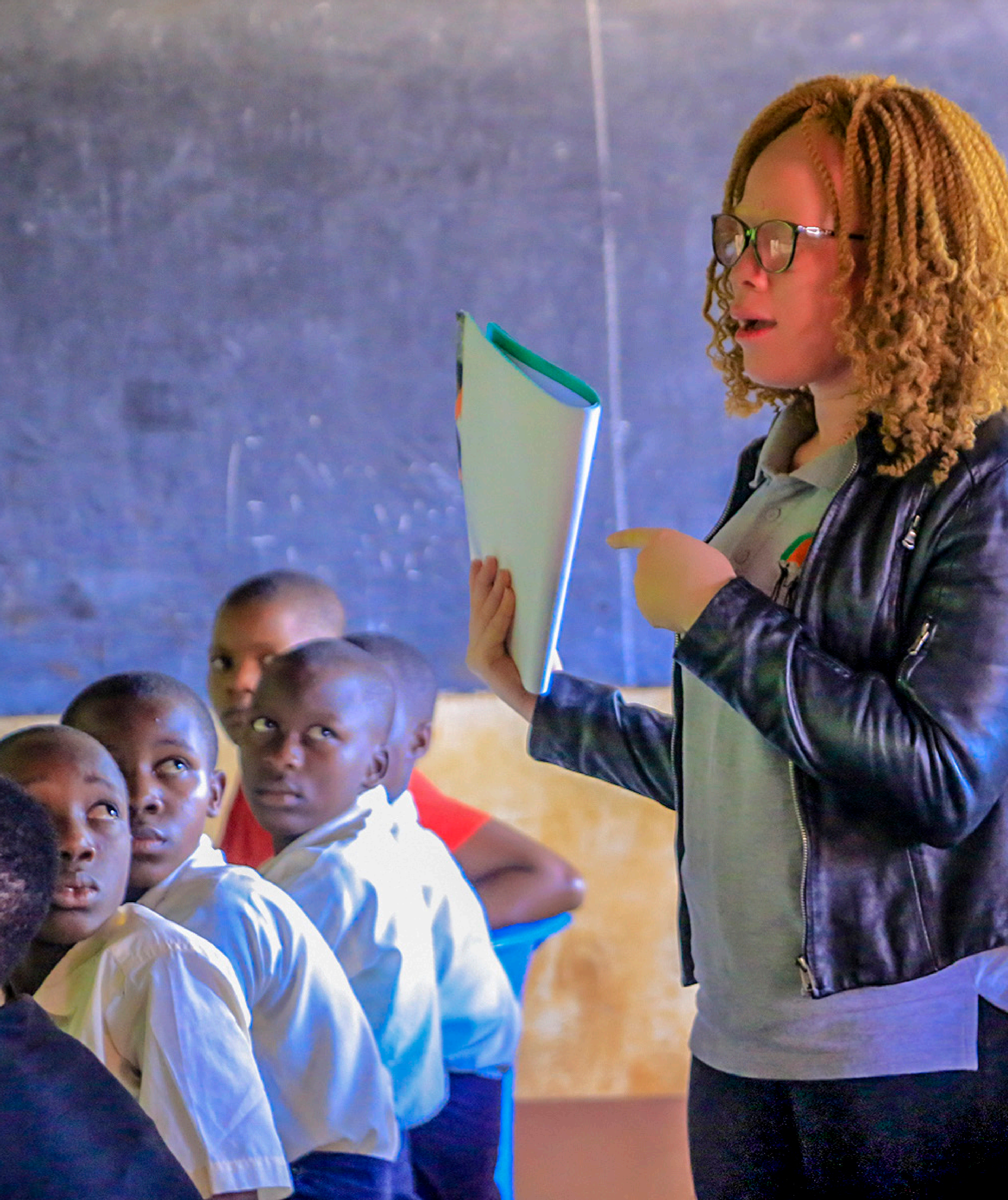
These are special skin protection lotions commonly referred to as sunscreens. Persons with albinism need to use them to protect their skin from developing lesions due to exposure to the sun.

17. 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 ultraviolet 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.

Conclusion

The journey through the pages of “Embracing Albinism - A Health Awareness Handbook,” seeks to beacon a comprehensive exploration of albinism, its various aspects, and the ways in which individuals and communities can support and empower those with this condition. Albinism, characterized by a lack of melanin, is rich with unique challenges and opportunities for understanding, growth, and advocacy for inclusivity for all.



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P. O. Box 3262–Kampala, Uganda
Kanyanya- Gayaza Road
+256 393 208 405
info@albinismumbrella.org
@albinismumbrell
http://www.facebook.com
www.albinismumbrella.org