



ALBINISM

An Information Booklet for Teachers in Sierra Leone



Sierra Leone Association of People With Albinism & Medical Assistance Sierra Leone

Lancaster University • Coventry University • University of Worcester • Standing Voice



Medical Assistance
Sierra Leone

ACTION ON SPECIALIST CARE

Introduction

This information booklet focuses on what albinism is and how it affects a child's learning. It contains practical advice to enable teachers and educators to help children with albinism to reach their potential in school.

Every child has a right to education and this booklet aims to help teachers understand the support needs of students with albinism. With the active support of their teachers, children with albinism can be very successful students and make a significant contribution to Sierra Leonean society.

The Sierra Leone Association of Persons with Albinism (SLAPWA) can offer additional support regarding accommodations for students, and training for teachers. We can answer questions on how students may be further supported. We ask teachers to inform students with albinism that they can access sunscreen information and other practical support from SLAPWA free of charge.



Finally, we all have a role to play in ensuring that children can learn in an environment that values them and their psychological safety. Our members tell us that bullying and name-calling has profoundly affected their mental health and in many cases has caused them to drop out of school. Let us all be very clear that bullying is not acceptable within our schools and work towards creating a place of learning where all students can feel safe.

Mohamed Osman Kamara, Director
Sierra Leone Association of Persons with Albinism

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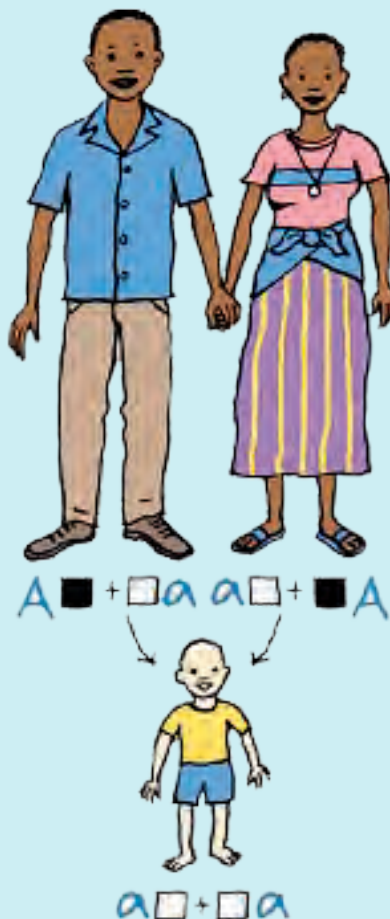
I. What is albinism?

A lack of dark pigment

Albinism is a rare, non-contagious, genetic condition that limits the body's production of the pigment melanin in the skin, eyes and hair.

Albinism occurs throughout the world. People with albinism are often very pale, visually impaired, and vulnerable to UV radiation from the sun.

Globally, 1 person in 18,000 has albinism. In sub-Saharan Africa, albinism is more common.



An inherited condition

Albinism is a genetically inherited condition. Sometimes there is only one person in a family with albinism, sometimes there are more.

Every person has two copies of a gene that produces melanin; one or both of these may carry albinism. There are different forms of this gene: the **A** form produces melanin while the altered **a** form does not.

If a child is born with albinism, this means their parents are both carriers **Aa**; the **A** form is dominant and produces melanin (so the parents have dark skin, hair and eyes). The child has inherited the **a** form from both their mother and their father, so they do not produce pigment. That is why they have albinism.

Albinism is a genetic condition that occurs at birth and lasts throughout life; it is not a sickness, disease or curse, and cannot be passed on through contact or touching.



EVERY TEACHERS ROLE

Teachers play an extremely important role in the lives of children with albinism. Aside from the immediate family, teachers bear the responsibility of helping a child with albinism grow, learn and realise his or her full potential in life.

Students with albinism may have experienced serious trauma in their life such as stigmatisation and neglect. This can have long-lasting effects including a lack of confidence and self-esteem. In school, this can prevent their ability to learn and develop as individuals.

It is important to be sensitive to the particular needs of students with albinism. Their vision impairment needs to be accommodated. In addition, love and respect should be shown to each student in order to build their self-esteem and confidence. People with albinism are the same as any other human being and have the right to be treated as such.

The teacher's response and attitude towards albinism will influence other students and affect the educational environment and achievement of children with albinism.



Teachers play a key role in:



Creating an ideal environment for learning



Discouraging bullying and facilitating acceptance



Helping children with albinism to integrate into school life



Dispelling misconceptions about albinism

Specific things that you can do to help:

- ✓ Ensure that the best practice outlined in this booklet is followed in the classroom and throughout the school
- ✓ Always be sensitive if disciplining pupils
- ✓ Stop the use of labels - such as Jus, Fenfu in Temene, Jaiwi in Mende, Pullijor in Fullah and 'Disappointed African' - and prevent references to students with albinism as 'albino'
- ✓ Use students' personal names at all times

Students with albinism who are supported and given the right opportunities can achieve like any other student.

2. Poor vision

Low vision, but not blind

Albinism is always associated with poor vision from birth, but not blindness. The degree of visual impairment differs between individuals and is static. This low vision starts at birth but will not worsen with age.

Children with albinism may not realise that their eyesight is worse than that of other children when they start school.

A lack of melanin pigment causes reduced pigmentation in the eye, increasing sensitivity to light and decreasing the ability of the eyes to absorb light.

As a result, people with albinism can experience discomfort in bright light and can often appear to be squinting or closing their eyes.

The front and back of the eye also develop differently resulting in a lack of precision or detail in their vision. In addition, the nerve connections between the eye and brain are also affected, which can lead to a number of eye conditions.

Given the right vision devices, appropriate classroom support and advice, many vision impairments can be improved.

Why low vision?

There are several eye conditions associated with albinism in Africa:

Nystagmus

Eyes that 'wobble' due to involuntary eye movements from side to side, which worsens when tired or stressed. Although the eyes move, people with albinism see a stable image.

Myopia (Short-sightedness)

Inability to see things clearly unless they are relatively close to the eyes.

Astigmatism

Blurred or double vision.

Strabismus or Squint

Both eyes do not work well together so one eye turns in or out relative to the other.

Photophobia

Extreme sensitivity to bright light. Dark glasses or a wide-brimmed hat will help reduce glare.



Approximately half of all students with albinism need strong prescription glasses that improve vision but do not completely correct it. With or without glasses, most people with albinism have to hold text very close to their eyes to read it clearly and comfortably.

In bright light, children with albinism find it more difficult to see and distinguish detail. In such conditions, it will take them longer to complete tasks involving reading and writing.

Some students also struggle to judge distances and speeds. As a result, they may have difficulties with fast-moving sports.





How teachers can help:

Assess the child's level of vision

Teachers should intervene immediately to support children with albinism who have low vision with strategies such as:

- ✓ Avoiding bright lights
- ✓ Allowing students to hold books and papers closer
- ✓ Sitting near the front of the class



Seeking an evaluation by a low vision doctor who can provide very important guidance and prescription glasses if needed. The doctor should provide a written or verbal report to the teacher and parents to guide whether special magnifiers or spectacles should be used daily.



Close observation by the teacher and a meeting with the child and their carers will help to reveal the child's level of functional vision

By developing an understanding of the nature, degree and educational implications of a child's visual impairment, teachers will be better able to make adjustments to accommodate their individual learning process.

Not Braille

Most children with albinism can see print if they are allowed to get close enough to the book. They do not need to learn Braille.

Low vision devices

Many children with albinism can benefit from low vision devices like magnifiers, but these must be appropriate to the needs of the individual and recommended by a low vision doctor. In general, persons with albinism in Sierra Leone require an enlargement of about 3-4 times to see the same small print as other students or adults. For near viewing, this means they can get closer to print by about 3-4 times but this may make their eyes tired and their neck and back sore after long periods of time. Frequent breaks should be allowed.

Near Magnifiers: Students may also use other devices including hand-held magnifiers, dome magnifiers and magnifying reading glasses. If a low vision doctor prescribes these, students should be encouraged to use them as they have been advised to do so.

For distance viewing, a monocular telescope of 3-4X magnification usually works well for seeing print on the blackboard.



Monocular telescopes: these are hand-held devices that are used with one eye. They magnify an image to make it easier to see. Generally, they are used to see things further away, such as a sign or a blackboard. Some may also use it for tasks that are closer, such as reading a textbook. Students should be encouraged to use their monocular in any situation where they feel it would help.



Teachers should understand the purpose of different vision devices and encourage students with albinism to use them. It is important for teachers to explain to the class the reason why the student with albinism has a monocular telescope to avoid ridicule or grabbing of the device.

Reading stands

Some students may benefit from a reading stand on their desk.

This will enable them to adjust texts to a comfortable distance.

Wooden reading stands are easy and cheap to produce.



UV-protective sunglasses

UV-protective sunglasses reduce the amount of light that travels into the eye, enabling people with albinism to see with comfort.

Students with albinism should be allowed to wear these sunglasses whenever they feel they need to, and should be encouraged to do so when in direct sunlight.

Prescription glasses

Prescription glasses are prescribed by professional optometrists or ophthalmologists (eye doctors) and are tailored to the specific eyesight of an individual. Ideally, the eye doctor is additionally trained in low vision and albinism, and can more thoroughly provide a low vision check or prescribe glasses and magnifiers of the correct power.

Even though prescription glasses do not completely correct the visual impairment of a person with albinism, they can significantly improve their vision, especially when the child is highly near-sighted or myopic which is common in the type of albinism commonly found in Africa.

Students should be encouraged to follow their optometrist's recommendations about wearing their prescription glasses.

Some students require glasses for long distance viewing and others for near vision and reading. It is very important to find out when and for what tasks the student should be wearing their prescription glasses.

Reposition the child with albinism

Make sure that students with albinism are positioned in the classroom where they are most comfortable. Depending on their vision needs, students with albinism might prefer to sit at the front, in the centre or on the left- or right-hand side. The direction of seating where they are most comfortable usually aligns with the position of their head that makes their nystagmus or shaking eyes slow down. Do not attempt to alter the head position of students with albinism as the tilt reduces their eye movements.

Students with albinism must be positioned so that they are not sitting in or looking into direct sunlight. Allow them to be mobile, to move close to the board to see and to move their desk to the best position at different times of the day.

Permit students with albinism to wear their hats indoors to help protect their eyes.

Present information on the blackboard clearly

The contrast of white chalk on a blackboard is best. Green and white boards are harder for people with albinism to see. White boards may have the best contrast but often produce glare from reflections. If using a white board, ensure that any glare from nearby windows is not reflecting in the students' eyes.

Write in big, bold letters on a clean board and organise text clearly.

Always describe with words and in detail what is being done so that students with albinism can follow the lesson.

It is particularly difficult for students with albinism to change focus repeatedly, so copying from the board to an exercise book will be much more difficult.

Allow a fellow student to read out what is written on the board or to share notes. If possible, photocopy your teaching notes for each person with albinism in the class.



Make tasks and materials accessible

Use the child's name to get their attention before instructing them.

If possible, students with albinism should be provided with their own copy of textbooks and teachers' notes so that they can read them at a closer proximity when needed. Textbooks and teachers' notes should be provided well in advance so that the student has extra time to prepare.

Provide a dark pencil or pen and allow the student to write in a size that suits them best. A black pen on white paper is easier to read than pencil.

Textbooks, teachers' notes and examination materials should also have clear and large print.

Allow extra time for tasks, including tests, to allow for the additional time needed to read the questions.

This is particularly important if the exam questions are provided in small or regular print, and if the exam papers are re-used or faded copies.

Each child is a unique individual and, where possible, adjustments need to be tailored accordingly. For further detail, see the Appendix: Low vision and recommended classroom modification.

3. Sun protection

Sun damage to the skin

Skin cancer is one of the major challenges facing people with albinism. Due to the lack of protective melanin pigment in their skin, people 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 and hard skin, with skin lesions which can develop into skin cancer.

Evolution of skin damage in persons with albinism



Skin cancer is preventable. Protection from the sun prevents cancer, saves lives and needs to start from an early age.



How teachers can help:

Monitor the skin of students with albinism

If you observe wounds that do not heal, ensure that the child goes to a clinic or hospital. Taking action could save the child's life. Encourage sun protection behaviour.

People with albinism must protect themselves from the sun every day (even on cloudy days). They should avoid sun exposure as much as possible.

They should:

- ✓ Wear a thickly woven (e.g. denim) dark coloured hat with a brim wide enough to cover the whole face, including ears and nose, and the neck
- ✓ Wear sunglasses to protect their eyes from glare
- ✓ Cover up as much skin as possible by wearing long-sleeved shirts and long trousers or skirts
- ✓ Use sunscreen with an SPF (sun protection factor) of at least 15 to protect parts of the body that are still exposed even when wearing protective clothing, such as the hands, ears, nose, forehead, cheeks, chin and neck
- ✓ Seek shade and avoid sun whenever possible, especially in the middle of the day. Encourage use of umbrellas.

‘Studies in Africa suggest that most people with albinism die from skin cancer between the ages of 30 and 40’.

(Report by I.Ero, UN Independent Expert, 2015).



Adjust the daily schedule of activities

Encourage integration and participation in all school activities, taking into account the visual impairment and sun sensitivity of children with albinism.

Arrange outdoor activities for early or late in the day, avoiding the middle of the day when damaging ultraviolet rays are strongest.

Try to protect the child with albinism from unnecessary sun exposure, for example, give them indoor tasks, and encourage indoor leisure activities.

Facilitate students with albinism to attend skin cancer prevention services (such as those provided by SLAPWA) where possible.



Sun damage is preventable



4. Supporting students with albinism in and outside the classroom

Academic performance

There are no cognitive or academic learning disabilities associated with albinism. Children with albinism, with appropriate support, should be expected to perform as well as any other student in the class.

If a student's academic performance is poor, the problem is likely due to low vision, which can seriously impair a child's access to learning.

When low vision is addressed, the student will perform as well as any other student. If a learning disability exists, it is a separate condition and must not be associated with albinism.

Social impacts of albinism

Albinism brings social and emotional challenges. Difficulty in holding eye contact and reading facial expressions can make social interaction challenging. This can easily be mistaken for shyness, rudeness or inattention.

Myths and superstitions about albinism suggest that those with albinism have special powers (for good or for evil). This is not the case. The only difference in people with albinism is in the amount of pigment they produce.

How teachers can help:

Raise self-esteem

The social and emotional impact of albinism inside and outside the classroom needs to be taken into account at school.

Encourage young people with albinism to achieve by stressing that they have the same potential as others.

Do not ask a student with albinism about their barriers to learning in front of the class. Tackle their difficulties sensitively and with the support of this guide.

Try to offer additional classes after school or in breaks to support children with albinism.

Lead by example

Stigma and discrimination can have a big impact on young people. Help to end name-calling and the use of common yet disrespectful labels

Call the student with albinism by their name, not their condition. This will contribute to and foster understanding and respect.

Encourage peer, family and community support

Children with albinism are easy to identify in the community. As the condition is hereditary, teachers should ask if there are other siblings or family members affected and encourage **all** children to attend school.

There is a misconception that children with albinism will die young and that it is not worth devoting resources to their education. Families should be advised that this is not the case and the right of every child with albinism to a quality education should be recognised and promoted.

Parents and guardians are important partners in providing information about their child's educational needs and support for their learning.



5. Recommendations to Headteachers

School management

The headteacher at every school where there is a child with albinism should allocate one teacher to one student, making him or her responsible for monitoring this specific student through their time at that school to make sure support is ongoing.

At the start of the school year, ensure that the children with albinism who were attending school in the previous year are encouraged to return.

If a new class teacher is teaching a student with albinism for the first time, make sure that the teacher is aware of their specific needs.

Find out about any support offered by the Ministry of Education, such as the provision of large print examination scripts.

Allocate a head or senior teacher to inform and train class teachers, and maintain contact with parents and guardians.

Record keeping

Monitor educational progress on a regular basis and identify strategies that assist individual students with albinism.

Keep a record so this information is retained, passed on to future class teachers, and shared within and between schools.

Appendix: Low vision and recommended classroom modification

Vision Task	Vision Function	Classroom modification/Low-Vision Devices (Functional Vision)
Reading notes/books in class	Resolution/low vision Contrast sensitivity	<ul style="list-style-type: none"> ● Allow leaning over or close viewing of paper/books ● Allow head turn to use best eye if one eye is preferred ● Wear prescribed spectacles for near viewing if needed ● Use hand or stand magnifier if available and preferred ● Provide large-print books (sized 2-3 times larger than usual) ● Provide copy of teacher lecture notes ahead of time
Seeing notes on blackboard	Resolution/low vision Contrast sensitivity	<ul style="list-style-type: none"> ● Wear spectacles prescribed for distance viewing ● Clean blackboard regularly, use white chalk ● If white board, shade window to reduce reflections/glare. Use dark markers ● Sit in front row ● Use 3 or 4x monocular telescope ● Compare notes with a peer/classmate to check for accuracy ● Instructor writing in block letters, test the size for student visibility

Vision Task	Vision Function	Classroom modification/Low-Vision Devices (Functional Vision)
Lighting/squinting	Photophobia Glare from windows	<ul style="list-style-type: none"> ● Sit away from bright windows (let student select seat) ● Overhead lighting should be evenly distributed (lights placed in the ceiling or around the edges of the room) ● If available, allow a flexible-neck floor or desk lamp if room is extremely dim <p>Allow wearing of sunglasses or tinted spectacles in class if student is especially light sensitive (should be worn over distance spectacles and coordinated with vision specialist).</p>
Best seating position	Nystagmus, null point Strabismus, better eye use	<ul style="list-style-type: none"> ● Allow student to turn head to any position to see the board ● Allow student to sit on the side or centre of the room to improve viewing angle for a head turn
Test taking	All of the above	<ul style="list-style-type: none"> ● Allow 1.5-2x times for completion, if written test question or instructions on board, create a printed paper copy for students with albinism to view up close ● Ensure seating in class is away from glare/windows ● Allow use of monocular telescope if transcribing from the blackboard
Computer/tablet use	Resolution/low vision Contrast sensitivity Glare sensitivity	<ul style="list-style-type: none"> ● Wear spectacles for near viewing, allow leaning toward the monitor ● Allow student to change the monitor settings to reduce background glare ● Allow student, or change settings, to enlarge text (accessibility modifications in the computer “settings”) ● Seat the computer away from a window/light so that glare is not reflecting off the monitor or coming from behind the monitor ● When using the internet, often using the mouse by holding down the left button, while using the scroll knob enlarges print on websites ● Place enlarged print and reverse contrast keyboard stickers on the keyboard keys

Source: Rebecca L. Kammer, 'Low Vision Rehabilitation and Albinism' in Jennifer G.R. Kromberg and Prasheila Managa, eds. Albinism in Africa (Elsevier, 2018), 151-169



“Accommodation in the classroom and a positive learning setting can be the difference between a child remaining at school or leaving education. With the right support all children can flourish”

Mary Penn-Timothy, Commissioner with Responsibility for Special Needs, Teaching Service Commission

Contact SLAPWA for advice, support, sunscreen, information on eye and skin care, advocacy and community.

Slapwa.sl@gmail.com | 099353368 / 076429890

This booklet includes information drawn from the following sources:

Dart, Gareth and Lund, Patricia, Teachers' Toolkit for Supporting Students with Albinism in African Classrooms (AIMZ: Albinism in Malawi and Zambia, 2014) (<https://eprints.worc.ac.uk/3736/>)

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Nystagmus Booklet for Teachers (The Nystagmus Network, 2016) Standing Voice Vision Ambassadors Training Booklet

We are grateful to Standing Voice (www.standingvoice.org) for permission to adapt this booklet for the Sierra Leone context, including the use of some photos.

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