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Albinism:
Information pamphlet for teachers

This young boy with albinism lacks the protective dark pigment of his father so will burn very easily in the sun

Supported in Malawi by:

Ministry of Education, Science and Technology

FEDOMA: Federation of Disability Organisation in Malawi
TAAM: The Albino Association of Malawi
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What albinism is ... and what it is not

A lack of dark pigment

Albinism in an inherited condition resulting in a lack of black pigment in the hair, skin and eyes, making those affected in Africa visibly very different from their dark skinned peers.

An inherited condition

Usually children with albinism are born to parents with typical black pigmentation; sometimes there is only a single affected child in a family, sometimes more.

How it is inherited

Unaffected parents who have a child with albinism are carriers of the gene that causes albinism; they have one functional copy of the gene, so they produce pigment, and one altered, non functional copy. If a baby inherits a non functional copy of the gene from each parent they will not produce melanin pigment and have albinism. The chance of this happening is 1 in 4 (25%) for each pregnancy.

'You see that from the same mother and father you have different children; some have albinism (like this young girl wearing a hat and glasses), others are black.'

Not contagious

Albinism is inherited, it is not 'caught' from others.

No special powers

Myths and superstitions about albinism suggest that those with albinism have special powers (for good or for evil) whereas the only difference is in the amount of pigment they produce. They may be rejected and ostracized, leading to low self esteem.

Every teacher's role

The teacher's response and attitude towards albinism will influence other pupils and affect the educational environment and achievement of this vulnerable group; teachers play a key role in:

- discouraging bullying and facilitating acceptance
- helping these children integrate into school life
- dispelling the misconception that those with albinism die young, so it is not worth putting family resources into their education.

The head teacher at every school where there is a child with albinism should allocate one teacher responsible for monitoring that pupil throughout their time at that school, to make sure that support is on-going.

Poor vision: variable but not progressive

Low vision

Albinism is always associated with poor vision from birth. At the start of school children with albinism may not realize their eyesight is worse than others.

Teachers should realize that a child with albinism will have low vision and intervene immediately to assist.

Not blind

The degree of visual impairment differs between individuals and is static. This low vision is present throughout life, but will not worsen with age.

Assess the level of vision

Close observation by the teacher will reveal the level of useful functional vision.

Teachers should not wait for an optometric or visual assessment by a specialist. This may never happen!

People with albinism find it difficult to follow moving objects such as a ball.

Not Braille

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

The cap worn here will help protect his eyes from the light ***inside*** *but would not protect his lower face or neck from the sun* ***outside.***

Low vision devices such as magnifiers enlarge text and may be helpful, but must be acceptable to the child.

The teacher should explain to the rest of the class why the magnifying device is necessary for the child with albinism to be able to see print.

Why low vision?

The list of eye problems associated with albinism makes it a challenge to get appropriate spectacles to improve their vision:

- Eyes that 'wobble' due to involuntary eye movements from side to side (called nystagmus) which worsen when tired or stressed; although the eyes move the brain adapts and they see a stable image
- Extreme sensitivity to bright light (photophobia)
- Poor sharpness of vision (poor visual acuity)
- Refractive problems (which can be corrected with spectacles)
- Squint.

Remember: Albinism causes low vision, not blindness!

Spectacles can improve vision for those with albinism and dark glasses will reduce glare. Note that the newspaper is held close to his eyes but this cap does not protect his ears, face or neck from the sun so is not suitable for wearing outside.

What this visual impairment means for the pupil with albinism

They will feel uncomfortable in bright light, will be slow to see, find it difficult to distinguish detail and to follow moving objects such as a ball. It will take them longer to complete tasks involving reading and writing.

It is difficult for them to judge the speed and position of a moving vehicle. Ideally someone should accompany them when walking along the road, to avoid accidents.

Low vision devices

Simple hand held magnifiers can help enlarge text and objects. Other pupils may, however, target these devices, wanting to try them 'for fun' so support will be necessary when they are introduced.

A reading stand on a desk may be useful to support the book and enable the child to read at a slant. Wooden reading stands should be easy to produce locally at a low cost.

The reading stand can be adjusted to suit the child's preferred reading distance.

Sun Protection

Sun damage to skin

Due to the lack of protective melanin pigment those 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. These can develop into skin cancer.

Teachers should monitor the skin of pupils with albinism. If they observe wounds that do not heal, they should ensure the child goes to a clinic or a hospital.

Myths about the skin

There is not a layer of skin 'missing' in albinism; the structure of the skin in someone with albinism is the same as anyone else, except that it contains very little pigment.

It is not true that the skin is immature or undeveloped and that exposure to the sun will help further development (like an immature fruit ripening in the sun). If a child with albinism is put in the sun they will burn, their skin will go red and then peel. This is dangerous; those with albinism should avoid the sun as much as possible.

Children with albinism can bathe in hot water like anyone else. This may cause their soft skin to go pink, but this will not last long and is not damaging. They do not have to wash in cold water.

Encourage sun protection behaviour

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

Both boys and girls can have albinism.

Here a young boy wears a wide brimmed hat and a long sleeved shirt to protect his sensitive skin from the sun.

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, although this is expensive and may not be easily available
- Seek shade and avoid sun whenever possible, especially in the middle of the day.

Nutrition

There is no special diet or food for people with albinism; they can eat the same food as others in the family.

Encouraging Inclusive Education

Early identification and intervention

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** of them to attend school.

Everyone with albinism has some degree of visual impairment; do functional assessment to gauge the level and intervene immediately to adapt the teaching environment.

All children have a right to education.

How teachers can help

Adapting their teaching style

'I would prefer to sit in front at the middle so that when the board is full with notes I am able to see from one end to the other.'

Find the best environment in the classroom (usually in the centre at the front, close to the board and away from direct light).

Permit them to wear their hats indoors to help protect their eyes.

Practical tips for teachers to assist a pupil with albinism:

1. Find the best environment in the classroom at a particular time of day (usually in the centre at the front, close to the board and away from direct light)
2. Allow them access to their own book so they can hold it close to their eyes
3. Permit them to wear their hats indoors to help protect their eyes
4. 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
5. Write in big, bold letters on the board and organize text clearly on a clean board
6. Always describe in words in detail what is being done so the pupils with albinism can follow the lesson or allow a fellow pupil to read out what is written on the board

'I don't see properly so sometimes my friends write notes for me and help me read the notes.'

7. Provide a dark pencil or pen and allow the pupil to write in a size that suits them best
8. Use a reading stand on a desk to adjust the text to a comfortable distance for the pupil
9. Allow extra time to complete tasks including tests
10. Provide large print material, especially for examinations
11. Encourage other pupils to assist them by sharing notes or by reading to them
12. Help them to use other clues to identify objects and people such as colour, shape, pattern and contrast. For example, a black pen on white paper is easier to read than pencil
13. Some people with albinism see better if they tilt their head to one side; allow them to adopt this position

Some people with albinism tilt their head to one side to a position where their eyes wobble least.

14. Explain to the other pupils why these adaptions are being made
15. Encourage peer, family and community support
16. Try to offer additional classes after school or in breaks.

'When reading a book, I don't have a personal book so we share in a group of 6 or sometimes 7; I have no chance to hold the book so I struggle to see properly. As a result I just sit in the group. I would prefer if I was holding the book.'

Adjust the daily schedule of activities

- Arrange outdoor activities for early or late in the day, avoiding the middle of the day when damaging ultra violet rays are strongest
- Try to protect the child with albinism from unnecessary sun exposure, for example give them indoor tasks and punishments and encourage indoor leisure pursuits.

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

Boys with albinism often prefer to wear baseball style caps, but these do not provide adequate protection from the sun.

This brimmed hat and glasses offer better protection.

School Management

Continuing education

- Nominate a teacher to monitor progress throughout the time at the school
- At the start of the school year ensure the children with albinism attending the school the previous year are encouraged to return
- If a new class teacher is teaching a pupil with albinism for the first time discuss their needs with other teachers and the head
- Find out about any support offered by the Ministry of Education, such as provision of large print examination scripts
- Allocate a head, itinerant or resource teacher to inform and train class teachers and maintain contact with parents/guardians.

Record keeping

- Monitor educational progress on a regular basis and identify strategies that assist individual pupils with albinism
- Keep a record so this information is retained, passed on to future class teachers and shared within and between schools.

Raising self esteem and avoiding hurtful name-calling

- Encourage young people with albinism to achieve by stressing they have the same potential as others
- Call the pupil with albinism by their name, not their condition.

'My fellow pupils don't talk bad about me because the headmaster said that no one should do that.'

The Albino Association of Malawi (TAAM) suggests using the term *'alubino'* for someone with albinism, from the English word. This avoids other derogatory terms that are sometimes used, like *'napwere'*.

If teachers use neutral terms, this will encourage pupils to do the same.

'The community should stop bullying and calling me bad names for me to be happy and play comfortably with friends at home.'

Supporting families

There is a misconception that children with albinism will die young and it is not worth devoting resources to their education. Counselling that this is not the case and helping to promote the rights of children with albinism, including access to education and full participation, will facilitate inclusion.

- Identify teacher responsible for liaising with parents/guardians
- Support and encourage families to se nd children with albinism to school
- Using this booklet, advise families and the community about albinism

Specialist and community support

- Use the skills of specialist itinerant teachers if available
- Harness support for families affected by albinism via community leaders in the church, Traditional Authority, Educational Offices and local community groups
- Facilitate support by family, friends, classmates, neighbours and advocates to help with daily activities such as homework and ensuring the child travels safely to and from school.

'The child with albinism should be protected by the parents at home and by the teachers at school. In the community it is the role of everyone.'

For more information contact:

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