

ALBINISM: INFORMATION PAMPHLET FOR TEACHERS



Fiji Albinism
PROJECT

Acknowledgements

The words used in this booklet have been based on the words originally written for a booklet of the same name for use in Malawi by:

Dr Patricia Lund (Coventry University, UK)

p.lund@coventry.ac.uk

Boniface Massah (TAAM: The Albino Association of Malawi)

bonmassah@gmail.com

Dr. Paul Lynch (University of Birmingham)

p.lynch@bham.ac.uk

The original drawings by Sheila Roberts and Viv Wong have been reimagined and redrawn in pencil for use in the Pacific Context by **Ms Naomi Waqa**

Development of this booklet in its original form was supported financially by:

- The Commonwealth Secretariat
- Coventry University
- Sightsavers Malawi

The original booklet is available freely online via the University of Coventry and can be used for any non-commercial purpose.

The Fijian publication of this booklet was supported by:

Rotary Club of Suva, Fiji

The Fiji Albinism Project

Ministry of Health and Medical Services

Ministry of Education, Heritage and Arts

Fiji Society for the Blind

Ministry of iTaukei Affairs

Improving Skin Health in Fiji and the Pacific Trust Fund, St Vincent's Hospital, Sydney, Australia

The Fiji Albinism Project

Email: fijialbinismproject@gmail.com

Tel: 3320066

Address: GPO Box 16346 Suva, Fiji Islands

Thank you to everyone who contributed to this booklet especially the families living with albinism in Fiji.



Index

Understanding the facts about albinism.....	
What is albinism?.....	3
Every teacher’s role	4
Poor vision – variable but not progressive	4
Why low vision?	6
What does visual impairment mean for a pupil with albinism?	7
Low vision devices.....	8
Sun protection	8
What strategies can you use in the classroom.....	
Encouraging inclusive education	11
How teachers can help.....	12
School management	15
Raising self esteem	15
What about strategies for support beyond the school gate	
Supporting families	16
Specialist and community support	17



Fiji Albinism
PROJECT

Understanding the facts about albinism

What is albinism?

A lack of dark pigment

Albinism is an inherited condition resulting in a lack of dark pigment in the hair, skin and eyes, making those affected in the Pacific visibly very different from their dark skinned peers. In ITaukei language people with albinism are called “Rea”.

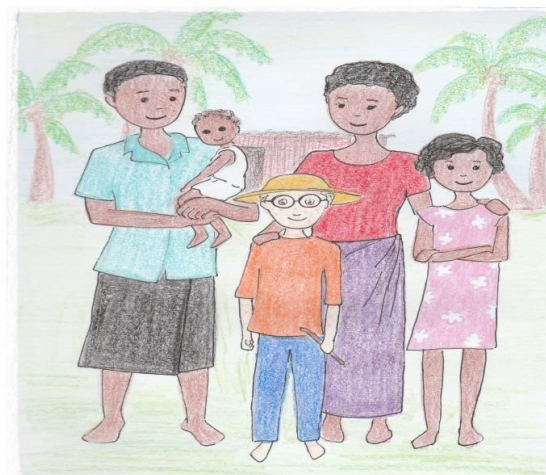
An inherited condition

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

How it is inherited

Albinism is inherited. Parents who have a child with albinism are both carriers of the gene that causes albinism. Sometimes only one child in a family is born with albinism, sometimes there are more. The chance of this happening is 1 in 4 (25%) for each pregnancy when both parents are carriers of the albinism gene. Albinism is no one's fault.

“You see that from the same mother and father you have different children; some have albinism (like this young boy wearing a hat and glasses) others are dark skinned.”



Albinism is not contagious

Albinism is NOT “caught” from others. However, people with albinism can often experience teasing, bullying and social isolation leading to low self-esteem.

Every teacher's role

The teacher's role is to have a positive attitude towards children with albinism. This will influence other pupils and affect the educational environment as well as creating opportunities of achievement for children with albinism.

Teachers must:

- Ensure the children have equal access and opportunity to educational resources as their peers
- Help these children integrate into school life
- Discourage bullying and facilitate acceptance



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 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. When beginning school, children with albinism should have compulsory eye testing, as some children may not be aware that they have low vision.

Not Blind

The degree of visual impairment differs for each child.

Assess the level of vision

Teachers need to observe the child with albinism closely to assess the appropriate visual aids and assistance the child may need.

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.

Low vision devices such as magnifiers to enlarge text and large print books may be helpful.

Allow the child the opportunity to identify which form of assistance is most suitable for their situation.

Make sure the child feels supported in the classroom.



The teacher should explain to the rest of the class why the magnifying device or large print is necessary.

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 (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

All children with albinism should be encouraged to have their eyes tested at an eye clinic.

Remember: Albinism causes low vision, not blindness!



Spectacles can improve vision for those with albinism. Holding the book close to their eyes may help the child read. When inside, some children may find wearing a cap helpful to reduce the glare.

When outside all children with albinism should wear a hat and dark glasses to reduce the glare and help protect them from the sun.

What does visual impairment mean for the pupil with albinism?

The child will probably feel uncomfortable in bright light, will be slow to see, find it difficult to distinguish detail and follow moving objects such as a ball. It will take them longer to complete tasks involving reading and writing. Their eyes will become tired and strained and may need to rest if completing intensive tasks.

The child may also have difficulty in judging the speed and position of a moving vehicle. Ideally someone should accompany them when walking along the road in order to avoid accidents.



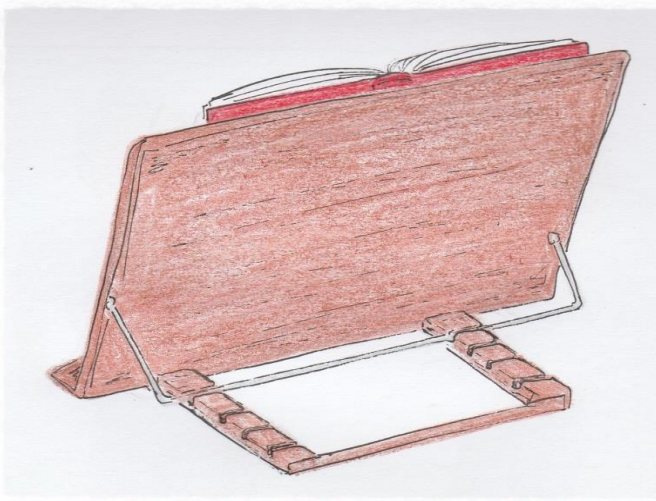
As the school day progresses, encourage the child to express their needs as they may need to make adjustments for their eyes.

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, sloped board or a stand to raise books and papers on a desk may be useful to support the book and enable the child to read at a slant. This helps the child maintain a better posture that will help prevent neck and back problems. Lighting is important. Ensure the child has good lighting to avoid their desk being in shadow.



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

Sun Protection

Sun damage to the skin

Due to the lack of protective melanin pigment people with albinism are extremely sensitive to the damaging ultraviolet rays of the sun, which will cause burning and ageing of the skin. Blistered and hard skin lesions may develop, which can turn into skin cancers.



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.

Information about the skin

People with albinism are not “missing” a layer of skin. 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 underdeveloped and that exposure to the sun will help further development (like an immature fruit ripening in the sun). If a child with albinism is exposed to the sun they will **burn**, their skin will go **red** and **peel**.

This is dangerous; people with albinism should **avoid** the sun.

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

People with albinism must protect themselves from the sun every day including cloudy days and 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, nose, and 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+ preferably 30+, 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 everyone else eats.

What strategies can you use in the classroom?

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; an assessment will gauge the level of intervention required for the child's learning.

All children have the right to access an inclusive education and feel supported at school.



*All children
have a right
to education*

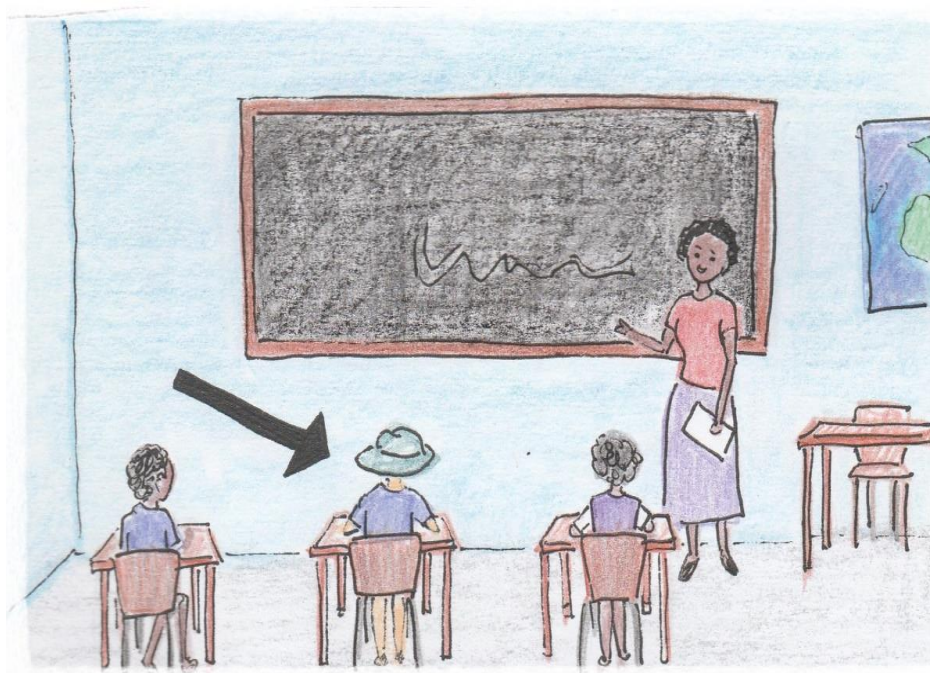
How teachers can help

Adapting their teaching style

Find the best environment for the child in the classroom. Allow the child to move around the class as they need. Ensure that they child can see the board and the teacher.



"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"



Ensure the child can see both the teacher and the board

Practical tips for teachers to assist a child 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 the child access to their own book so they can hold it close to their eyes
3. Permit the child to wear their hats indoors to help protect their eyes
4. Allow the child to be mobile, to move close to the board 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 children with albinism can follow the lesson or have the child next to them 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 them"

7. Provide a dark pencil or pen and allow the child 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 child
9. Allow extra time to complete tasks including tests
10. Provide large print materials, especially for examinations
11. Encourage other children to assist them by sharing notes or by reading to them
12. Help the child 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
14. Explain to other children why these adaptations are needed
15. Encourage peer, family and community support
16. Consider additional classes after school or in breaks if needed
17. Allow the child to take rests if their eyes are straining or tired

Adjust the daily schedule of activities

- Encourage inclusiveness in all aspects of school activities
- Arrange outdoor activities for early or later in the day, avoiding the middle of the day when damaging ultra violet rays are strongest



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



People with albinism need to be encouraged to wear hats at all times when outside. This will provide protection from the sun. Broad brimmed hats and sunglasses offer better protection

School Management

Continuing education

- Nominate a teacher to monitor the child's progress throughout their time at school
- At the start of the school year ensure the children with albinism, who attended the school the previous year return
- If a new class teacher is teaching a child with albinism for the first time discuss their needs with the new teacher
- Find out about any support offered by the Ministry of Education, such as provision of vision aides, large print material, electronic devices or support teachers
- 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.

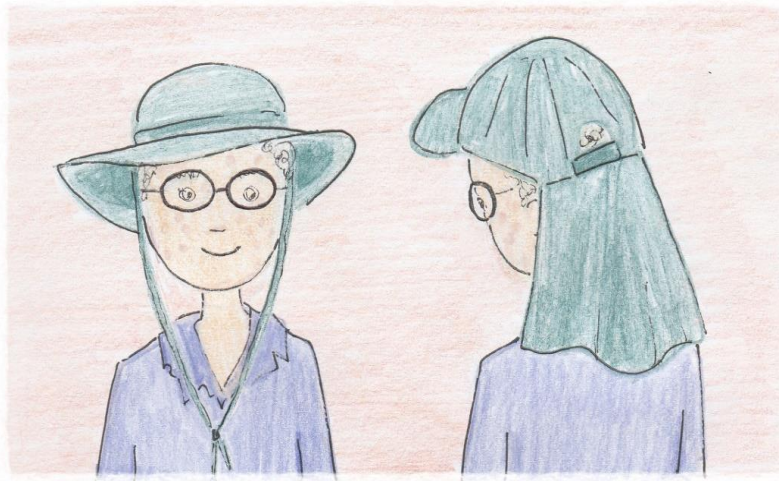
Raising self-esteem

- Reassure the child that albinism does not impact on their intelligence
- Encourage the child to achieve by stressing they have the same potential as others
- Focus on the child's abilities and celebrate their achievements
- Always refer to the child by their name, not their condition
- Advocate on behalf of the child and teach them to advocate for themselves
- NEVER tolerate bullying behaviour



What about strategies for support beyond the school gate

Supporting Families



There is a misconception that children with albinism are not as clever as other students. This is not true. Children with albinism have the same capability as all children. They need to be supported with the right tools and encouragement to reach their potential.

The rights of children with albinism need to be respected. This includes access to education and full participation, which will facilitate inclusion and develop their full potential.

- Identify teacher responsible for liaising with parents/ guardians
- Support and encourage families to send 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

- Liaise with support services where possible
- Encourage the community to support families who are affected by albinism
- 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.



“It is the role of the community to protect and care for a child with albinism whether at home or in schools.”

Where can I find more about albinism in Fiji?

Families with a member who has albinism may want to join The Fiji Albinism Project, which promotes the welfare of people with albinism in Fiji. For information about the project, this booklet and the albinism eye and skin clinics you can contact:

The Fiji Albinism Project

Email: fijialbinismproject@gmail.com
Tel: 3320066
Address: GPO Box 16346 Suva, Fiji Islands

References:

Supporting students with albinism by Sandra George can be found at Albinism Fellowship of Australia

www.albinismaustralia.org

National Disability Coordination Programme

www.education.gov.au/national-disability-coordination-officer-programme