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Living with Albinism in Malawi:
Information for children and young people

Two members of the same family: one has dark skin, the other has albinism

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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How am I different?

You have a condition called albinism which means you do not produce dark pigment (called melanin) in your hair, skin and eyes.

In other ways you are just like others.

Both boys and girls can have albinism.

How albinism is inherited

My parents are both black, why was I born different?

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

We all carry two copies of an inherited unit (called a gene) that causes this condition.

Your parents are carriers: they have one copy of this gene that is working to produce pigment (so they are black). The other copy is altered. It is not working and does not produce pigment.

The mother and father each pass one copy of this gene to their child.

How albinism is inherited

Fertilization: aa resulting in a child with albinism

In this case the sperm from the father and the egg from the mother both carry the altered form of the gene (called a). The baby will not produce pigment and will be born with albinism.

You have received an altered copy from both parents, so you do not have a gene that is working to produce pigment. This is why you have albinism.

I have brothers and sisters who are black. How is this?

They have received a copy of the gene that allows pigment to be made. This could come from either the mother, the father or from both parents.

Some families have some children who are black, while others have albinism.

Vision

Is my eyesight different from others?

Yes, because your eyes lack pigment this changes the structure of your eyes. They ‘wobble’ from side to side which makes it difficult to see detail and means your eyes are very sensitive to bright light.

How does my eyesight differ?

You see things more slowly and may find it difficult to judge movement and speed, for example when a ball is thrown or a car is travelling towards you.

My sister also has albinism but her eyesight is better than mine. Why is this?

People with albinism all have reduced eyesight but this can vary from person to person, just like in people without albinism.

This chart is used to measure your eye sight.

If you have albinism you will have difficulty reading these letters at a distance.

Those with ‘normal’ vision can read these letters on the chart.

Will my eyesight get worse as I get older?

No, your eyesight will change as you get older, but you will not lose your sight.

Will I go blind because I have albinism?

No, albinism causes low vision, not blindness.

Should I learn Braille?

No. If you can see when you hold the book or object close to your eyes you do not need to be taught Braille.

Most people with albinism have sufficient vision to read without Braille.

Remember albinism causes low vision, not total blindness.

How can I manage with reduced/ poor eyesight?

Here are a few tips, which you probably know already:

- Use colour, shape or patterns to help identify and find objects
- Ask people to speak so you can recognize their voice and can follow lessons in class
- Do tasks like reading early rather than late in the day, when you are fresh
- Some people with albinism find that their eyes 'wobble' less when they tilt their head.

The Chimodzi family. Virginia has albinism whereas her mother and aunt are black.

When Virginia started school she did not realize her friends could all see the board while she could not. She asked for help from her teachers and now she is a teacher herself.

Is there anything that can help me see better?

Prescription glasses can help you read.

Magnifiers that you hold in your hand will make letters and numbers larger. Donors may be able to provide these.

Remember the most important thing is how you use the vision you have!

These children are wearing their hats in class to reduce glare. They are leaning close to the paper while drawing.

Why am I so sensitive to the sun?

Having albinism means that you do not have black pigment that helps protect your skin and eyes from damage and discomfort caused by the sun's rays.

A young boy with albinism leans close to the paper to do a detailed drawing. His skin shows damage from the sun.

How can I protect myself from the sun?

- Wear a wide brimmed hat every day to protect your skin and eyes
- Wear long sleeved shirts and long trousers or skirts and sunglasses
- Choose dark, tightly woven material such as denim to give good protection from the sun
- When buying clothes hold them up to the light and choose ones you cannot see through
- Seek shade or remain indoors whenever possible, especially in the middle of the day, when your shadow is longer than you are.

A young girl with albinism wears sunglasses to protect her eyes from the glare of the sun and seeks the shade of a building during the middle of the day.

Sun Protection

A young girl wears a thick, wide brimmed denim hat to protect her eyes from bright light indoors and leans close to the paper to draw.

Will I go dark if I stay in the sun?

No. Your skin will go red, it will burn, blister and peel.

This can be painful so avoid the sun as much as you can.

If you have wounds on your skin that do not heal, ask to go to the clinic or hospital.

How does the sun damage my skin?

- UVA are ultra violet sun rays that age your skin
- UVB rays cause your skin to go red and burn
- Both damage your skin and cause sores.

How does sunscreen help protect my skin from the sun?

It contains chemicals that help protect your skin from the sun.

How do I use sunscreen?

If affordable, use sunscreen that protects against UVA and UVB, with an SPF (sun protection factor) of at least 15.

Sun Protection

- Apply this to all parts of your skin not protected by your clothes, especially your face and hands
- Apply to dry skin at least 15 minutes before going into the sun
- Apply during the day; at night you can use any cream or Vaseline to soften your skin.

This is one type of sun protection cream.

It has an SPF (Sun Protection factor) of 30 to protect the skin from the sun.

This lotion has a green colour so you can check you have covered all parts of your skin exposed to the sun.

Not all sunscreens are green!

Even if you use sunscreen you should still wear clothes to protect your skin from the sun and try to avoid the sun during the middle of the day!

When should I protect my skin from the sun?

Every day! All year round! Even on cloudy days.

Damaging UVA rays reflect off water, sand and concrete and pass through glass.

This means your skin can burn if you are out on a river or lake, even if you are wearing a hat.

Is there any special food I should eat?

No, you can eat the same food as everyone else in the family.

I go red when I bath in hot water. Should I use cold water?

No, the redness is temporary (it is not the same redness as you get when out in the sun!). You can use hot water to wash.

How can my friends help me?

- Join you playing in the shade or indoors rather than out in the sun

Friends playing inside during the heat of the day.

- Walk with you so that you are safe crossing the road and help you learn how to get around at school and in the community

Children of one family where two have albinism and two do not. Those with good sight help the others to get around.

- Call you by your name when they see you, so that you recognize their voice, even if you do not see them clearly
- Read out loud to you
- Help you copy notes from the board in school and share their notes with you afterwards.

How can well wishers help me?

- Buy you a hat with a wide brim, long trousers or skirt or a shirt with with long sleeves
- Buy you sunglasses

How others can help you

Buying hats in a local market.

Wearing a hat, sunglasses and long sleeves.

- Provide you with sunscreen lotion (although this is expensive and not freely available in Malawi)
- Buy you a magnifier to make letters and numbers easier to see
- Tell others about albinism to help educate the community.

How can my teachers help me?

- Allow you to sit at the front of the class, in the middle so you can see the board
- Let you wear your hat indoors, to help protect your eyes from bright light
- Let you move to the board to see more clearly what is written
- Give you your own book to read, rather than sharing, so you can hold it close to your eyes
- Write in big, clear letters on the board
- Provide tests and exams in large print
- Help you to avoid being in the sun as much as possible
- Give you indoor duties (and punishments!)
- Explain to other pupils why you are treated differently e.g. always sit at the front because you do not see as well as others.

Show this booklet to your teacher.

Plan your day

Plan every day to try to avoid the sun and make sure your clothes cover as much of your skin as possible.

- Make sure you are wearing clothing to protect your skin and have your hat before leaving home
- Do reading and learning earlier in the day when you are fresh rather than later when your eyes are tired
- Plan outdoor activities such as sport, gardening and farming for early in the morning or later in the evening when the sun's rays are not as strong.

Does albinism give you special powers?

No, you have the same ability and potential as others.

These drawings were done by Blessings, a young boy with albinism who has a talent for drawing.

Remember: everyone has the right to a good education.

Where can I find out more about albinism?

The Albino Association of Malawi (TAAM)
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