Flashcards Albinism



- **These flashcards contain information about working with people with albinism in low resource areas.**
- **These Flashcards are made for the use of fieldworkers.**
- **These flashcards are based on the information about albinism from the RehApp.**

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The goals of the flashcards are:

- To support you in your work. You can keep these flashcards on your phone (offline) or in your bag.
- To improve knowledge and skills in providing basic rehabilitation services for people with albinism and their families.
- To meet the needs of people with albinism and their families.
- To improve the quality of life of people with albinism and their families.

Index

Albinism

You can use these flashcards to:

- Learn about the implications of albinism for the person and their family.
- Guide your visits to families that have a family member with albinism by:
  - Giving information on albinism.
  - Making an inventory of the needs of the person with albinism and his/her family.
  - Setting goals for a person with albinism.
  - Discussing interventions with the family.
  - Keeping client records.
  - Monitoring process.

Note:

*These flashcards contain information about albinism. These cards **do not** replace the knowledge and skills of doctors and therapists. We advice you to refer the person to a doctor or therapist if needed.*
*The content is organised according to the **ICF domains.***

Information about Albinism	
	Introduction
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Albinism: content

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Card 1

Introduction

What is albinism?

Albinism negatively affects the production of melanin in the body, the pigment that colours skin, hair and eyes. It's a lifelong condition.

The bodies of people with albinism may produce a reduced amount of melanin, or no melanin at all. This can affect their colouring and their eyesight. Some people with albinism have white hair, some have brown or ginger hair. The colour depends on how much melanin the body produces.

Albinism is caused by genetics. If both parents carry the gene for albinism there is a 25% chance their child will have albinism and a 50% chance their child is a carrier of albinism. Carriers may not have albinism but can pass on the gene to their child.

Albinism is neither a curse nor a punishment, it is a genetic condition and occurs in families all over the world. Though natural, albinism is a rare and relatively unknown condition. While in Europe the rate of people with albinism is 1 in 20,000, in certain parts of Africa it is estimated that 1 in every 5,000 children are born with albinism. Elsewhere, these figures might even be higher.

Consult a medical expert when in doubt, e.g. in the case of partial albinism such as the absence of pigment in specific parts of the body only.



Consequences and risk factors

Because of the light skin, people with albinism easily contract sun burns, especially in countries around the equator. Eventually this may lead to skin cancer. To prevent this, it is important to use sunscreen lotion and wear a hat, sunglasses and long sleeves.

Also, the reduced amount of melanin can cause eye-problems resulting in poor vision. That is why a child with albinism may need extra support with reading in school.

Furthermore, some cultures have myths about people with albinism. They believe people with albinism have special powers – which is simply not true. Traditional healers may use hair, nails or body parts of a person with albinism to make potions or ointments – often expensive and always ineffective. As a result, people with albinism are occasionally attacked, trafficked and sometimes even killed. It is a serious violation of human rights.

Card 2

Introduction

Diagnosis

The most accurate way to diagnose albinism is through genetic testing. However, this is often not necessary since we can all easily distinguish between a child with albinism and a child without albinism. Even pale children do have some colour in their eyes, skin and hair.

Field workers and health workers can advise parents of a child with albinism to prevent the child from sunburn and to consult a doctor to check the eye-sight of the child. Fieldworkers and health workers can also advise the school teacher to allow the child to sit in front of the classroom to be able to read the blackboard.

For more recommendations, please refer to the **RED** cards: Body Functions and Structures.

Questions and answers (Q & A) on albinism

***Q**: Is albinism a disease?*

A: No, it is a genetic condition. You cannot contract albinism. Furthermore, it is not contagious.

***Q**: Is albinism a disability?*

A: Yes, especially when the eye-sight is affected the special support for reading is required. Furthermore, people with albinism cannot be outside in the sunshine without wearing protective clothing such as a hat, sunglasses, long sleeves and sunscreen lotion.

***Q**: Is there a cure for albinism?*

A: No, there is no cure for albinism.

***Q**: Is the mother to blame for giving birth to a child with albinism?*

A: No, the genetic disorder that causes albinism can be in both the mother's and the father's bloodline. Or in both.

***Q**: Are people with albinism intellectually or physically less able than others?*

A: No, though lack of physical (outdoor) exercise may have negative consequences on the development of their muscles and general wellbeing.

***Q:** Can people die of albinism?*

A: No, although their chance of dying from skin cancer is considerable.

Card 3

Introduction

Some advice

If you are a person with albinism, you should:

- Stay out of the sun as much as possible.
- Wear protective clothing as much as possible when going out during daytime e.g. wide-brimmed hats, long-sleeve shirts, long trousers, sunglasses etc.
- Use sunscreen lotion frequently - check if the government has an arrangement in place to supply them for free.
- Visit a doctor to examine your eye-sight and prescribe reading glasses, and to visit a doctor in case of skin problems.
- Inform yourself about your condition and on how best to protect yourself.
- Talk about your condition with others: family members, fellow students, co-workers, local leaders, friends.
- Involve others: ask for help, guidance and/or protection whenever necessary.

If you are close to a person with albinism, you should:

- Help children stay out of the sun as much as possible.
- Employers, teachers and others should accommodate requests by people with albinism to stay out of the sun.
- Schools should permit alterations that allow uniforms to become more sun-protective.
- Make sure they use sunscreen or sunblock lotion frequently. In some cases these can be obtained free of charge through government programmes for people with albinism.
- Suggest to visit a doctor in case of visual problems or skin problems.
- Inform yourself about albinism.
- Encourage the person to talk about the condition with others who are close to him or her.
- Get involved: offer help and/or protection whenever necessary.

[Insert pho… …s
represen…
impair…
functi…
e.g.:…



Body functions & structures:
Information and
Actions to take



Card 4

Body functions & structures

Causes

Albinism is caused by a 'defect' in one or several genes that produce or distribute melanin. The defect may result in the absence of melanin. Melanin is a dark brown to black pigment occurring in the hair, skin and iris of the eye in people. The absence of melanin causes (part of the) skin, hair, etc. to be white.

Prevention and treatment

It is not possible to prevent albinism. If albinism occurs in the family of the father or mother, chances increase they have a child with albinism. The defective gene may be dormant for several generations though.

There is no treatment for albinism. With certain precautions and some consideration by others, people with albinism can live quite normal lives. A climate with daily sunshine will be a more challenging environment to live for someone with albinism.

Signs & symptoms

Although there are different types of albinism with various degrees of residual pigmentation, these are the most common characteristics:

- The skin lacks colour altogether or is much lighter than usual. There can be patches of skin that have an absence of colour. Later in life, moles, lumps or growth can occur. Freckles are often present and can change in size, shape or colour. When these changes are noticed, these should be reported to a medical doctor.
- As the eyes lack colour, the blood vessels visible can cause the eyes to look red. Rapid and involuntary eye movements is also common with albinism.
- The facial and other hair of a person with albinism is either completely white or a yellowish orange. Though lacking in colour, the hair itself has the same characteristics as other hair and can be combed, braided, dyed and cut as usual.

People with albinism stand out much more in an environment where people are generally dark skinned. Furthermore, the health risks people with albinism run in tropical countries are higher than in temperate climates.

Card 5

Body functions & structures

Complications

- People with albinism get sunburned easy because of the absence of pigment (melanin) in their skin. Regular sunburn can lead to painful and lethal skin cancer.
- Melanin in the eye directs the (sun)light to the sensitive areas inside the eyeball. The lack of melanin may cause a variety of visual complications, ranging from headaches to lack of focus and blurred vision. Visual impairment complicates daily life and has an impact on study, work as well as social activities. In some cases, blindness may occur.
- A lack of physical, outdoors exercise and a lack of social activities may result in mental and/or psychological problems as well as a lack of physical fitness.
- Standing out as an individual with albinism in a dark-skinned environment may lead to feelings of isolation, to being bullied or avoided and, all too often, to being prevented from fully participating in society.
- As mentioned in the introduction, particularly in some African cultures people with albinism are subject to violence. It is because of superstition and traditional beliefs saying that people with albinism have special powers. Traditional healers may use hair, nails or body parts of a person with albinism to make potions or ointments that are sold to people looking for prosperity. As a result, people with albinism are occasionally attacked, trafficked and sometimes even killed. It is a serious violation of human rights. Faced with such stigma and danger, people living with albinism in these communities tend to live in fear – and all too often in isolation.

Card 6

Body functions & structures

The skin of a person with albinism is particularly vulnerable to sunlight though it functions in the same way as any other skin. Actions to take to protect the skin:

1. Stay out of the sun, especially when the sun is high.
2. Use sunscreen or sunblock, whichever is available.
3. Use protective clothing including long sleeves, long dresses, shoes and maybe even gloves.
4. Not all clothing is equally effective: coloured and denser-woven clothing allow less light penetration. Make sure the clothing is breathable though, to reduce the risk over overheating.
5. Wear protective headgear such as caps, headscarves or hats and sunglasses. Do not forget to protect the neck and ears! When using a hat, make sure the rim is at least 3 inches (8 centimetre) wide.

Please note that sunscreen lotions or sunblock may not always be readily available. Sources where they can be obtained should be identified. These might be quite far away. Furthermore, they often are costly, do not protect for a long time and are not always waterproof. A constant supply is best.

6. Umbrellas can also help protect oneself, especially when a mother is carrying a child with albinism or for people who get overheated easily.
7. If the skin is severely sunburnt, other lotions should be applied in order to cure the skin. Consult a medical doctor or pharmacist for advice.

The eyes of a person with albinism are also very sensitive to sunlight. The eyes may therefore be unable to focus or move continuously and involuntarily. Actions to take to protect the eyes:

1. Avoid direct sunlight.
2. When outdoors, a cap, hat or headscarf may offer some protection to the eyes as well.
3. Sunglasses (shades) offer additional protection, even indoors.
4. When experiencing visual problems, always consult a doctor.

Dark hair, in tropical countries, is one of nature's ways to protect people's heads and brains against the light and heat generated by the sun. Actions to take to protect hair:

The hair of a person with albinism does not need special care and can be treated the same way as his or her siblings treat their hair.



Can the consequences of albinism be mitigated? Some advice to persons with albinism.

SLIP, SLAP SLOP! Will protect your skin

- ❑ **SLIP** into protective clothing: coloured and denser-woven clothing allow less light penetration and this will protect the skin and also internal organs.
- ❑ **SLAP** on a wide brimmed hat, cap or headscarf (and dark glasses or shades) in order to protect head, eyes and ears.
- ❑ **SLOP** on protective lotion such as sunscreen lotion or sunblock, at least 2 to 3 times a day before going out into the sun. The UV protection factor should be high for better protection.

Besides, regular glasses may very well compensate any visual complications arising from albinism. Therefore people with albinism should be diagnosed by an eye-doctor as soon as possible.

People with albinism should avoid direct sunlight as much as possible. Outdoor activities including household chores should be kept to a minimum or carried out in the early morning or in the evening.

It is important to check regularly for skin changes, such as:

- a new mole, lump or growth
- freckles or patches of skin that change in size, shape or colour.

When these changes in the skin are noticed, the person should be referred to a medical doctor as soon as possible.

Some advice to authorities:

In addition to glasses, many people with albinism require devices such as magnifiers, monoculars and cell phones that can take photos of objects and signs at a distance in class and in everyday life. These devices are highly important for access to education and employment for people with albinism.

According to the United Nations Convention on the Rights of People with Disabilities governments have the obligation to support the provision of these as part of reasonable accommodation and to ensure that people with albinism are not discriminated against (refused such accommodation) in these domains.

Card 7

Body functions and structures







Activities & participation:

Information and
Actions to take

[Insert photos/illustrations representative of the impairment for activities and participation; e.g.:]



Card 8

Activities & participation

Participation

There are many actors that could and should contribute to the health, participation and general well-being of a person with albinism:

- ❑ The family, including mothers, fathers, children, other siblings, aunts, uncles, grandparents etc.
- ❑ The community, including neighbours, teachers and local authorities such as chiefs, police and medical workers including traditional doctors.
- ❑ All over the world but especially in Africa, people with albinism have been the victim of ignorance, outright discrimination and violence. This means they often cannot participate in and contribute to society to the best of their capacities.

Actions to take:

Local health workers should reach out to the family and community of people with albinism to raise awareness and provide correct information on the condition.

- Emphasis should be on treating people with albinism the same as they would treat any other person – with some restrictions.
- Household chores should be indoors as much as possible.
- Time spent outdoors during daytime, e.g. in order to attend school or participate in sports, should be limited.
- School teachers should be aware of the visual impairments that can come with albinism and support the child accordingly.
- Help should be offered when needed, e.g. in order to obtain sunscreen lotion or sunblock.

Education and awareness raising

Education is crucial to defend and improve the quality of life of people with albinism, both to people with albinism themselves and to their environment.

- ❑ Awareness raising and education are needed to the public in general. It is key to overcome negative attitudes towards people with albinism in the community.
- ❑ People with albinism have the same rights (to health care, education, work, to safety, to vote etc.) as everybody else.
- ❑ Authorities, religious leaders and society at large should always defend the interests of people with albinism.

Actions to take:

- Awareness raising and education can be given to and in families, schools, community centres and religious institutions.
- It is important to reach out to policy makers, religious leaders, employers or trade unions, healthcare workers, the police and others, including traditional doctors.
- People with albinism themselves should take action and leadership in public engagement.

People with albinism should be involved as much as possible in these educational and outreach activities. Testimonials are a strong tool to increase awareness about the challenges of people living with albinism.

Card 9

Activities & participation

At school and at the workplace

Children with albinism may experience different problems at school. These include:

- It may be hard for them to read the blackboard in the class.
- Sometimes they may not be able to read at all.
- Loose clothes such as headscarves and their sensitive skin may prevent them from fully participating in outdoor activities such as physical education.
- Bullying and ignorance may make them feel insecure, unhappy and even drop out of school.
- Schools have to make sure pupils with albinism can participate fully in all activities. Schools should also permit alterations that allow uniforms to become more sun-protective.

- Likewise, employers have the responsibility to protect employees with albinism.
- Working conditions should be adjusted to accommodate employees with albinism.



Actions to take:

- ❑ Like with other visually impaired children, it may be advisable to put children with albinism who have visual impairments in front in the classroom.
- ❑ Some children are better off with braille or special education.
- ❑ Pupils with albinism should be involved in any adjustment made for them.



- ❑ Employers have the responsibility to make protective clothing available to employees with albinisms if necessary or, preferably, assign indoor tasks.
- ❑ Working conditions could be adjusted to accommodate requests by employees with albinism, e.g. shade should be provided and lights could be dimmed.
- ❑ Employees with albinism should be asked what adjustments would benefit them.
- ❑ Employees with albinism have the right and therefore should be allowed to defend their own interests at the workplace.

[Insert photos/illustrations representative of the impairment for personal factors; e.g.:]



Personal factors:

Information and

Actions to take



Card 10

Personal factors

Personal wishes and needs

The most notable aspect of albinism is a person's unusual appearance. The white hair and skin of a person with albinism stand out, even in countries where most of the population is light skinned. Albinism is a powerful factor from the moment of birth and often a child with albinism provides for a dramatic contrast to the family and community.
However, a person with albinism has the same needs and desires as anybody else and with some care can live a meaningful life like everybody else.

Mental health

Strangers, but also community members, will often make unwanted and unkind comments about the appearance of a person with albinism. Because of their condition, children with albinism often cannot interact with their peers as they would like to. Therefore, a child with albinism often feels isolated not only in physical appearance but also in the conduct of everyday life.
On top of that, children who live in countries where people with albinism are subject to traditional beliefs may live in fear of being attacked.

Health burden

In spite or their desire to 'blend in', this is hard to accomplish due to the risk of skin problems or visual impairment. The desire to participate in the short run (e.g. in sports activities outside, working in the field) could lead to serious health issues in the future.

Social skills and boundaries

The above may lead to a series of negative consequences not directly related to albinism. For instance, staying indoors all the time may lead to loneliness or poor physical shape. Standing out, or being ridiculed, could lead to low self-esteem and underperforming at school, in the family and elsewhere.

In countries were people with albinism also run a (perceived) risk of being attacked, kidnapped, mutilated or even killed simply for having albinism, confidence in community members may be low. This will be all the more so if authorities do not show any interest in their situation or do not follow up on reports of danger.

The pressure they may feel to minimize the differences between themselves and the people around them make them deny they have albinism, thereby losing touch with a very important aspect of one's identity and not pay enough attention to protective measures.

Card 11

Personal factors

Mental support

For those people with albinism who fell victim to kidnapping or assault, a lack of protection or frequent discrimination, these traumatic experiences may be hard to cope with. Mental support by those around them is crucial.

The role of caregivers, family members and others near to people with albinism, is very important. They are supposed to provide more than a family: they should provide safety and a true 'home' in order for a person with albinism to reach the best of their potential.

Peer counselling

The role played by peers is also important, especially when a child develops into an adult. Parents cannot take care of a person forever. Peers (friends, neighbours, classmates, co-workers) are the bridge between the individual and society at large. They are also a buffer between a sometimes hostile outside world and offer protection, assistance and advice.

Authorities

Authorities such as teachers, religious leaders, government employees, medical personnel and, last but not least, field workers play a crucial role in community life. They set the stage for people with albinism, disseminate information about the condition and protect the specific interests of people with albinism.

This should not be too different from their usual roles.

After all, people with albinism are just that: people. With albinism.





[Insert photos/illustrations representative of the impairment for environmental factors; e.g.:]

Environmental factors:

To be taken into consideration



Card 12

Environmental factors

Can the consequences of albinism be mitigated? Some advice to those around persons with albinism.

- ❑ First and foremost, family members, friends, co-workers etc. of people with albinism should be informed about and involved in any issue that relates to them, their health or social environment.

- ❑ School teachers and employers should recognise the fact that people with albinism often (though not always) have poor eyesight so they should sit close to the instruction, be it a blackboard or demonstration. They could be excused from exercising or working outdoors during daytime, in direct sunlight such as sports or agricultural activities, unless protective measures (sunscreen, protective clothing) are taken.

- ❑ Parents should minimize outdoor daytime chores for their child with albinism, such as fetching water, weeding, herding cattle or construction work. There is no need to spare children with albinism: they are just as good in doing the dishes, preparing food, cleaning the kitchen or making clothes as anybody else as long as these are indoors activities (although they may require glasses).

- ❑ With these precautions taken, people with albinism can perform any task just as well as other people with their capacities.



Awareness campaigns

Awareness campaigns can be helpful in providing people with correct information about albinism. Leaflets with attractively presented information are one option to spread the word.

Actions to take:

- Nurses, local influencers and people with albinism themselves can be asked to speak about the condition on the radio, tv or the internet to promote awareness.
- Social media can also be used to demystify albinism. It is important to involve faith-based organisations and traditional healers, family members and others.
- People with albinism should be allowed to speak for themselves. In many countries, they have organised themselves in ways comparable to Disabled Peoples' Organisations (DPOs). Their contact details can be found on the internet or via social media and they can be involved in outreach activities.
- Often, these DPOs work with individual 'role models': people with albinism that speak the local language and can provide first-hand experiences to the public.
- International Albinism Awareness Day is commemorated annually in many countries on June 13th.
- In some countries, people with albinism may run the risk of falling victim to physical violence. If this is the case in your country and if the authorities such as the police turn a blind eye towards this situation, they should participate in awareness sessions as well.

Social attitudes and risk factors

Social attitudes toward albinism are often like those experienced by other disability and minority groups. These attitudes include a lack of understanding, fear of the unknown, and prejudice based on appearance.

By teaching about albinism and giving people correct information, social attitudes may change.

Health care workers and midwives should be among the priority audiences. Training programs should focus on early intervention linked to vision impairment and the prevention of skin cancer.



Card 13

Environmental Factors

Card 14

Environmental Factors

Protection

There are still incidences of violence against people (mostly children) with albinism. It is important to protect these children and to give them a feeling of safety, security and comfort.

Especially in villages all people ought to be informed about albinism and in particular the village leader, influential people such as religious leaders and elders, and of course midwives, health workers and teachers. A point of contact should be designated when people with albinism are at risk.

The local police needs to be informed about threats so they can anticipate when necessary. It is important for them to know where the people with albinism live so they can patrol and provide safety.

The government and the leaders need to know about the situation of people with albinism. If there are any problems, these should be dealt with by the competent authorities.





Family counselling

Although a natural phenomenon, albinism is a rare occurrence. Families where a child with albinism is born, may therefore not be aware of what happened to them, why it happened to them and what to expect in the future. Family counselling could prevent people in the family from being 'blamed' for the condition of the child. Fieldworkers are in the perfect position to prevent families falling apart over a child with albinism while at the same time answering questions the community may have.

Adaptations

Adaptations at home, at school or at the workplace to accommodate children, youngsters and adults with albinism, are not difficult. Other than protective clothing (see card 4 in the RED section of these flashcards) or visual aids such as glasses, adjustments could include (but are not limited to) providing shade, allowing the person to sit closer to the blackboard or the presentation, and to reschedule outdoor chores or sports activities to earlier or later moments in the day.

Authorities

Political, religious and other authorities should recognise that, in spite of their small numbers, explicit care should be given to people with disabilities (including protective legislation) in order for them to be included in their environment and in order to be able participate in society to the best of their abilities.

Superstition

Unfortunately, many violent acts against people with albinism, especially children, have been reported from many parts of the world. Some of these reports in particular from Africa have been outright gruesome as ignorance has often been combined with witchcraft, superstition and the desire to make money over the bodies of people with albinism. This card debunks a number of the myths surrounding albinism:

- The body parts or hair of a person with albinism, used in whatever form, do **not** cure any disease.
- Having sex with a woman with albinism is **no cure** for sexually transmitted infections.
- People with albinism eventually die, like everybody else. **They do not just 'vanish'.**
- People with albinism do **not possess supernatural** powers, and neither do their hair or body parts.
- Body parts of people with albinism are sometimes used for amulets, ointments or medicine which are sold on the black market. Not only is this **illegal** everywhere and can be severely punished by the authorities, the practice is ineffective: amulets based on these body parts do **not** bring good luck or success.

Actions to take: do's and don'ts

- Learn about albinism from reliable sources.
- Talk to people with albinism and ask their opinion on issues.
- Inform them of their condition, protect them and learn how they can protect themselves.
- Inform those around them, their community, employers and others about albinism.
- Do not involve people with albinism in outdoor activities in broad daylight.
- Involve experts like eye-doctors to improve the daily lives of those living with albinism.
- Advice they see dermatologists regularly to prevent skin cancer.
- Do not discriminate against people with albinism and respect their rights.
- Do not blame anybody for having a child with albinism.
- Do not engage in illegal activities involving people with albinism and inform the authorities if there are signs these activities may take place.
- People with albinism or their caregivers could visit their local office in charge of people with disabilities for assistance for reasonable accommodation.
- And remember: SLIP, SLAP, SLOP!

Card 15

Environmental Factors

Card 16

Environmental Factors

What can you do as a CBR worker?

In normal circumstances, overexposure to direct sunlight is the main risk for people with albinism. You should advise them, their family and community to cover their skin at all times when out in the sun.

Later in life, it is important to check for skin changes. A person should be referred to a medical doctor when there are changes such as:

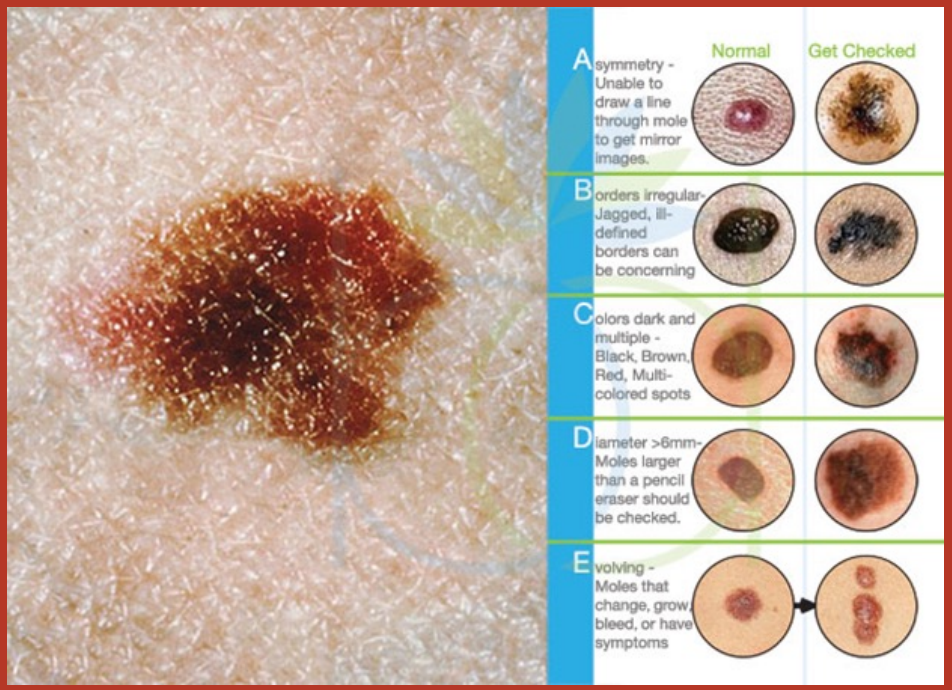
- A new mole, lump or growth
- Freckles or patches of skin that change in size, shape or colour
- Bleeding without any apparent reason.

Many people with albinism suffer from one or more visual impairments including short-sightedness, long-sightedness, cross-eyedness, rapid involuntary eye-movements and maybe even blindness.

If you feel one or more of the above is the case, you should refer the person to an eye-doctor as soon as possible.

The eyesight of people with albinism often suffers from exposure to direct sunlight. As being outdoors in broad daylight cannot always be avoided, you could recommend the person wear sunglasses and at the very least a broad rimmed cap which also protects the neck and the ears.

Regular glasses can also improve sight as this may reduce the rapid involuntary eye movements.



What should you ALWAYS do as a CBR worker?

Albinism is a rare but not an extraordinary condition. Make sure you talk about this disability with those concerned and provide them with proper information. Also, make people aware of the tools available to mitigate discomfort caused by albinism, such as sunscreen lotion, sunglasses, headscarves, long sleeved dresses etc.

Card 17

Colophon

For the development of the albinism chapter of the RehApp, we particularly want to express our gratitude for the valuable contributions of Frank Bron, Anne Kuijs, Ikponwosa Ero, Toon Sanders, …

This was made possible with the support of: