



# What is Albinism?

## ALBINISM

Albinism is a rare, non-contagious, genetically inherited condition occurring in both genders regardless of ethnicity, in all countries of the world. BOTH the father and mother must carry the gene for it to be passed on even if they do not have albinism themselves. The condition results in a lack of pigmentation in the hair, skin and eyes, causing vulnerability to sun exposure and bright light. Almost all people with albinism are visually impaired, with the majority being classified as “legally blind”. While numbers vary, in North America and Europe it is estimated that 1 in every 20,000 people have some form of albinism. In Tanzania, and throughout East Africa, albinism is much more prevalent, with estimates of 1 in 2,000 people being affected. The term “*person with albinism*” (PWA) is preferred to the term “albino” as it puts the person before the condition.

### Albinism is world wide

- **Albinism** affects people from all races: Black, White, Asian - every race has their own persons with albinism (PWA). See map (on page 6) showing persons with albinism across the world

### How does a person become a PWA ?

- Every PWA inherited the condition from **both** parents - mother and father. Both parents of a PWA, whether they are albino or not, **must** carry the genetic trait of albinism before a child with albinism can be born.
- When both parents carry the albinism trait (and neither parent is albino) there is a one in four chance (or a 25% chance) at each pregnancy that the baby will be born with albinism.
- Normal pigmented children born to such parents might also carry the genetic trait for albinism. Such children may in turn, pass the trait to their own children.



## Why do PWA have a “white” appearance

- Most children with albinism are born to parents who have normal hair and eye color for their ethnic backgrounds.
- A PWA is unable to produce the usual amounts of pigment or colour called *melanin*.
- This is why people with albinism have little or no pigment in their eyes or skin, or hair or in all of the above.

## Types of Albinism

- **Albinism only affecting the eyes.** This is called Ocular albinism (OA), and is much less common. Most cases are recorded in males. Children with OA may have skin and hair colour that are normal but slightly lighter than those of other family members.
- **Albinism affecting the skin, hair and eyes.** This is known as OCA or *Oculocutaneous* (pronounced ock-you-low-kew-TAIN-ee-us) albinism. This is the most visible form of albinism in Tanzania.
- Using DNA research, 4 forms of OCA are now recognized – OCA1, OCA2, OCA3 and OCA4; some of these are further divided into subtypes. In each category and sub-category of OCA, the degree of colour/melanin apparent in the individual varies.
- **Albinism plus:** Researchers have also identified a type of albinism that comes with additional characteristics. One of these is known as *Hermansky-Pudlak Syndrome* (HPS). In addition to albinism, HPS is associated with bleeding problems and bruising. Some forms are also associated with lung and bowel disease. HPS is a less common form of albinism but should be suspected if a person with albinism shows unusual bruising or bleeding.

## CHALLENGES OF ALBINISM

### 1. Vision Problems, Treatment & Rehabilitation

- People with albinism always have problems with vision that are not completely correctable with eyeglasses.
- Vision problems in albinism results from abnormal development of nerve connections between the eye and the brain due to their low or lack of colour/melanin.
- The degree of vision impairment varies with the different types of albinism and most people with albinism generally have low vision.
- Most however can use the vision they have for many tasks including reading.



- Most persons with albinism do not use Braille.
- A small number people with albinism have sufficient vision to drive a car.

### Treatment & Rehabilitation

- PWAs often show a combination of any of the following:

NAME OF CONDITION	CONDITION	TREATMENT or REHABILITATION (where available)
<b>Nystagmus</b>	regular movement of the eyes, side to side or in circular motion	Surgical intervention today <b>minimizes</b> but cannot completely cure nystagmus
<b>Strabismus:</b>  includes “crossed eyes” ( <i>esotropia</i> ), “lazy eye” or an eye that deviates out ( <i>exotropia</i> )	Muscle imbalance in eyes	For <i>strabismus</i> , surgery may improve the appearance of the eyes  In the case of <i>esotropia</i> or “crossed eyes,” surgery may help vision by expanding the visual field (the area that the eyes can see while looking at one point).
<b>Photophobia</b>	Sensitivity to bright light and glare	PWAs need light to see just like anyone else. Sunglasses or tinted contact lenses help outdoors. Indoors, it is important to place lights for reading over a shoulder rather than in front.
<b>Near or far sightedness.</b>  Usually with <i>astigmatism</i> or some blurriness	far-sightedness or near-sightedness	Various optical aids are helpful to people with albinism including bifocals, strong prescription reading glasses and bioptics* (glasses which have small telescopes mounted on)
<b>Foveal hypoplasia</b>	No normal development of the inside surface of the eye that receives light-known as the retina	See photophobia
<b>Optic nerve misrouting</b>	nerve signals from the retina to the brain do not follow the usual nerve routes	

\*Some countries permit driving with biotic lenses for some PWAs



## 2. Skin Problems and how to prevent them

- People with many types of albinism need to take precautions to avoid damage to their skin caused by the sun.
- Damage to the skin can be avoided by regularly wearing sunscreen lotions, hats and sun-protective clothing which is clothing that covers skin from exposure to the sun.

## 3. Medical Challenges & how to avoid them

- In many countries, most people with albinism live normal life spans and have the same types of general medical problems as the rest of the population.
- Those with additional conditions such as *Hermansky-Pudlak Syndrome* may have a shortened life span by lung disease or other specific challenges.
- In countries with sunny & hot or tropical climates like Tanzania, persons with albinism who do not use skin protection may develop life-threatening skin cancers.
- Persons with albinism in such countries must use appropriate skin protection, such as sunscreen lotions rated 20 SPF or higher and proper clothing to enjoy outdoor activities and a normal life span.

## 4. Social Challenges & how to remove them

- People with albinism are at risk of isolation because the condition is often misunderstood.
- Social stigmatization can occur, especially within communities where other family members have dark skin and appearance.
- Families and schools must make an effort to include children with albinism in group activities.
- Contact with other persons with albinism, or others who have persons with albinism in their families can be most helpful.



## 5. Educational Challenges & how to overcome them

- Due to significant vision impairment most persons with albinism cannot read from the blackboard in a normal classroom set-up.
- Teachers and educators must make extra effort to re-organize the classroom so that persons with albinism are positioned in front of the class and moved closer to the blackboard as needed.
- This re-positioning must be done so that the person with albinism is **not** staring into sunlight to see the blackboard.
- To enhance re-positioning, the blackboard must be kept “black” at all times so that the contrast of the white chalk may enhance read-ability.
- If re-positioning fails, teachers and educators must be prepared to photocopy their notes and give copies to each person with albinism in their class.
- Exams, teachers’ notes and other printed/photo-copied hand-outs must be clear and with large enough print.
- If needed, extra time must be granted for exam-writing for the persons with albinism. (Actual time plus half of actual time is suggested). This is especially important if the exam questions are provided in small or regular print, and if the exams are re-used/faded copies.
- For day-to-day support, teachers and educators may find it useful to assign a capable student to each person with albinism for peer support in the learning process.
- Further details for teachers and educators of persons with albinism are available in a small easy-to-read handbook: QUICK GUIDE for TEACHERS available at <http://www.underthesamesun.com/resources>



FIGURE 1

Albinism worldwide



What is Albinism?



## **RESOURCES**

### **NOAH**

The National Organization for Albinism and Hypopigmentation

**<http://www.albinism.org>**

### **POSITIVE EXPOSURE**

Rick Guidotti

**[www.positiveexposure.org](http://www.positiveexposure.org)**

### **VISION FOR TOMORROW**

The Vision for Tomorrow Foundation

**[www.visionfortomorrow.org](http://www.visionfortomorrow.org)**

## **EXPERT OPINION**

**Dr. Murray Brilliant**, Geneticist. Interview on Discovery Channel's *My Shocking Story: Albino Crisis* / Part 2 – (12:55 to 13:38). See

**<http://www.yourdiscovery.com/web/my-shocking-story/first-5-minutes/>** for information.