



QUICK GUIDE

for

TEACHERS

& Educators of Persons with Albinism

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Dear Teacher and Educator,

YOU ARE IMPORTANT!

Teachers and Educators play an extremely important role in the lives of students with albinism (SWA).

Aside from the immediate family, Teachers and Educators bear the responsibility of helping a SWA grow, learn and ultimately realize his or her full potential in life.

When you, the Teacher or Educator, read this *Quick Guide* and practice its Steps, you are positively transforming the lives of your SWA.

We, at Under The Same Sun, pledge to support your efforts in carrying out the following Steps to the best of our ability. Please do not hesitate to contact us for relevant assistance.

Sincerely,

Under The Same Sun Team¹



IMPORTANT NOTICE

Under The Same Sun is very pleased to share its information resources such as the document you are currently reading. More resources such as this are available on our website: www.underthesamesun.com/resources.

Unfortunately, we are unable to provide other types of resources including financial support, scholarship, donations of sunglasses, clothes or other form of assistance – to countries outside of Tanzania.

Our finances, physical and human resources, as well as our Education Scholarship Program are all limited to Tanzania.

We appeal to all especially Non-Governmental Organizations and other groups serving persons with albinism, to consider this as our operating constraints and not as a rejection of their goals.

We thank you in advance for your understanding; and join you in hoping for an effective use of this *Quick Guide* to improve the lives of persons with albinism.

The UTSS Team



ABOUT THIS GUIDE

This Quick Guide for Teachers and Educators of Persons with albinism is general information only. It should not be taken as medical or academic advice for particular situations. All information provided here has come out of the collective work and personal experience of UTSS' staff and affiliates including those living with albinism.

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ABBREVIATIONS

PWA	Person(s) with albinism
SWA	Student(s) with albinism
UTSS	Under The Same Sun

Accessibility

Visual: If this *Quick Guide* is inaccessible for a particular person or purpose, please contact UTSS to see discuss how we can be of assistance.

Language: This *Quick Guide* is also available in French and Swahili



UNDER THE SAME SUN

ALBINISM WORLDWIDE

ALBINISM WORLDWIDE
WE ARE NOT ALONE

Albinism is a non-contagious genetic condition occurring in all countries of the world. BOTH the father and mother must carry the gene for it to be passed on. Albinism is a lack of pigmentation in the hair, skin and eyes, resulting in low vision as well as vulnerability to sun exposure and bright light.

David - Canada

Harry - Puerto Rico

Sisters - United Kingdom

Isabelle - Cameroon

Matzan - Malaysia

Brooke - China

Desha - Russia

Noah - USA

Jayde - Japan

Gladysmira - Panama

Keke - India

Siri - Mali

Mere - Fiji

Amanda - Brasil

Tina - Uganda

CK and Daphne - Kenya

Smile - South Africa

Tanzania

Lauren - Australia

Ciana - New Zealand

POSITIVE EXPOSURE
The spirit of albinism
www.positiveexposure.org

UNDER THE SAME SUN
www.underthesamesun.com

UTSS Official Summary of 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 persons 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 1,400 people being affected. The term “*person with albinism*” (PWA) is preferred to the term “albino.”



EYES

Almost all PWA have visual challenges. Most cannot see things clearly from distances.

WHAT YOU CAN DO

1. HELP YOUR SWA SEE THE BLACKBOARD

STEPS TO TAKE:

i. Use only “Black” Boards

- Green Boards and White Boards are harder to see for SWA. If Green Boards and White Boards are the only options you have, please talk to our staff about obtaining a blackboard.

ii. Keep Blackboards “Black”

- This is necessary so that the contrast of the white chalk may enhance readability.
- Where it is absolutely necessary to use the green or white board, please keep green boards at their greenest and use only white chalk on them.
- Keep white boards at their whitest while using only black pens on them.

iii. Re-positioning the SWA

- Teachers and educators must make extra effort to organize the classroom so that the SWA is positioned in front and as close to the blackboard as needed.
- Depending on the visual needs of the SWA, he or she might be more comfortable with front and centre or front and far right or front and far left. Please work with the SWA to determine which position is best.
- Re-positioning must be done so that the SWA is not staring into sunlight to see the blackboard.ⁱⁱ





EYES CONTD.

iv. Head Position

- Most SWA have a permanent eye movement, whereby the eye moves from side-to-side. This is called “nystagmus.” This movement is normal amongst SWA and does NOT cause the SWA to see the world shaking.
- The eye movement contributes to reduced vision; thus most SWA will often tilt their head in a slanted way to reduce the eye movement.
- When you see this tilted head position in the SWA, **PLEASE** do not reposition OR attempt to reposition the head posture of the SWA.

v. How You Write

- **SPEAK WHILE WRITING:** SWA are more active learners when they are able to listen and write. This technique is generally preferable by SWA.
- Change your writing style to clear print.

For Example, *this is a door* is very difficult for a SWA to read

whereas **This is a door** is likely more legible to the SWA

- Write only on the portion of the blackboard that is most visible by your SWA.
- Increase the size of your handwriting on the blackboard until the SWA can see it.
- **NOTE:** Increasing the size of your print on the blackboard does not always work for all students. This is because one SWA does not always have the same visual level as another SWA.
- When increasing the size of your print on the blackboard does not work, go to the following steps:



EYES CONTD.

vi. **Photocopy and provide your notes to the SWA:**

- Teachers and educators must be prepared to photocopy their notes and give copies to each person with albinism in their class.
- These must be provided within reasonable time. Preferably some time before the relevant class or lecture so that the SWA might have some time to prepare in advance.
- If the notes are confidential, they should still be provided if they are necessary for learning. In such a case, the SWA may be asked to sign or promise that the notes they receive are confidential.
 - a. Photocopying the notes of a capable student is not ideal but acceptable.
 - b. Assistance with photocopying is available through UTSS at no cost to you.

vii. **Slanted Desks**

- When possible, allow the SWA to use a desk with a slanted top. This reduces the distance between the SWA and his or her work thus allowing the SWA to see his or her work better in a comfortable position. ⁱⁱⁱ



viii. **Peer Mentorship:**

- Always link a reliable academic student with a SWA in the class so that he/she can assist in things such as reading, note-taking, and general peer mentoring.
- In choosing a peer mentor, be sensitive to the dynamic of the relationship between the SWA and the mentor you choose.
- If the pairing does not work, end it and find another peer mentor.

ix. **Glasses**

- Even though most SWA will need or currently use prescription glasses, these often do not completely correct visual challenges.
- With or without glasses, most SWA have to hold text very close to their eyes to read it clearly and comfortably.



- Each SWA relies on their glasses for various reasons. Some may need it for clarity, some for distance, or some for reading, while others for all of the above.

EYES CONTD

- Be understanding and kindly refrain from enforcing a glasses-wearing pattern in your SWA which has not been sanctioned by the professional who prescribed the glasses or the SWA.
- Because the prescription glasses of SWA are expensive, please help them care for them to prevent breakage or loss.

x. **Allow the use of technology:**

- Your SWA might want to use small hand-held devices such as a monocular, or a magnifier. These ought to be permitted as they tend to enhance visual capacity.



A hand-held magnifier



A Monocular

- In higher education, such as University or college, permit the use of a recorder for capturing lectures. This might be helpful for the SWA to playback as a form of review.



EYES CONTD

2. HELP YOUR SWA READ & WRITE PRINTED MATERIALS

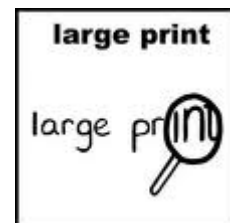
STEPS TO TAKE:

i. Enlarge Exams and Other Handouts:

- Exam questionnaires, teachers' notes, and other printed/photo-copied hand-outs must be clear and with large enough print.
 - a. Please work with the SWA, and/or UTSS staff to determine the appropriate size of print for the Student.
 - b. Assistance with photocopying is available through UTSS at no cost to you.

ii. Provide Extra Time for Exams:

- We suggest that extra time must be granted for exam-writing for the student with albinism.
- Actual exam time plus an additional half of actual exam 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.
 - a. If extra time is granted it is advised that the SWA writes their exam in a different location from their peers so that timing logistics can be better coordinated.^{iv}





SKIN

THE SKIN CHALLENGE:

PWA have little or no skin colour otherwise known as pigment. Skin colour or pigment is needed to protect all persons from the sun and sun burn. With little or no pigment, PWA must always dress with protective clothing or use sunscreen lotion if available. Without these, the PWA is at strong risk (especially in sunny countries) of getting and dying from skin cancer.

WHAT YOU CAN DO TO HELP:

1. PROTECT YOUR SWA FROM THE SUN



STEPS TO TAKE:

- i. **Protective Clothing** – This is the most important and the most readily available. Advise the student to wear long sleeved shirts and a hat that shield him or her from the sun, especially when outside.
- ii. **Sunglasses** – Permit students to wear sun glasses/shades when outdoors or indoors (as needed).
- iii. **Exemption from Outdoor activities** – Please exempt the SWA in your class from such activities unless the activity can be moved to a shaded area. Please encourage SWA to seek shaded areas whenever possible.
- iv. **Sunscreen Lotion** – When available, ensure that your SWA uses sun protection cream on a daily basis. This could be used to protect the small areas of the body (hands, ears, nose, forehead, cheeks, chin and neck) that are still exposed even while wearing protective clothing. UTSS office may be able to help you obtain sunscreen if available.



*Some Sun protective
Gear*



TEACHING

TEACHING A SWA:

There are no cognitive or academic learning disabilities associated with albinism. If a SWA has poor academic performance, the problem is likely due to low vision. When low vision is addressed, the SWA will perform like all other students in the class.

If a learning disability exists, it is a separate condition and must not be associated with albinism.

WHAT YOU CAN DO TO HELP:

1. GUIDE YOUR SWA IN HIS OR HER LEARNING

STEPS TO TAKE:

- i. **Follow-up with progress:** Frequently ask your SWA if they are doing okay and if they understand their school work. Ask if there is anything you can do to help. Talk to him or her one-on-one so that shyness will not be a barrier to your finding the truth.

- ii. **Peer Support:** For day-to-day curricula and extra-curricula support, teachers and educators may find it useful to assign a capable student to each person with albinism for peer support.





SENSITIVITY:

BE COMPASSIONATE

SENSITIVITY IS KEY:

Most SWA have undergone difficult trauma and horrible experiences. Many live in fear and continue to suffer from these experiences. Suffering from trauma can interfere with concentration and hinder learning.

WHAT YOU CAN DO TO HELP:

1. GUIDE YOUR SWA IN HIS OR HER LEARNING

STEPS TO TAKE:

- i. **UTSS recommends that NO corporal punishment be used for the SWA's academic shortcomings for the following reasons:**
 - The SWA's academic shortcoming is often a low vision problem and not an intelligence problem.
 - It could also be related to previous trauma which can result in difficulty in concentrating.
 - Also, because of mis-understanding about albinism, many SWA have been neglected and not allowed to develop their study skills.
 - Therefore, punishing a SWA for academic difficulties is like punishing someone for having low vision, for being neglected and for being traumatized. NO ONE should be punished for these reasons.
 - It would be better to ask the SWA about some of their barriers to learning and why they might be having difficulty with their school work.
 - Do not ask in front of the class or in an embarrassing manner.
 - Tackle their difficulty with the steps in this Guide. If there are no relevant steps in this guide, please contact UTSS for assistance.



RESPECT

RESPECT HELPS LEARNING:

Respect ought to be shown to each SWA. Respect includes treating each SWA like other students while appreciating their particular needs as summarized in this Guide. It also includes adherence to the human rights of SWA including the right to dignity and safety. Lastly and most importantly, respect is key to building self-esteem and confidence which in turn enhances learning.

WHAT YOU CAN DO TO HELP:

1. LEAD BY EXAMPLE IN TREATING YOUR SWA RESPECTFULLY.

STEPS TO TAKE:

i. **Help end name-calling and the use of common yet disrespectful labels**

Lead the class in stopping the use of labels: “Zeru-Zeru, Ma-albino, Mzungu, Whity, Deal, Ankara, and other names more commonly used in your locality.

Lead the class in stopping reference to a SWA as “albino.” To refer to someone as “albino” is to equate a human being to their most visible condition: albinism. This is contrary to global efforts to advance the dignity of *all* persons.

Try to use and lead the class in using more respectful terms including “person with albinism or student with albinism.

More importantly, use the SWA’s given name to refer to him or her. This will contribute to, as well as foster understanding and respect.



- ii. **Help end the following lies** and help **foster understanding of the truths** that follow.

LIE: Bad luck, sickness or death can come from a SWA.

TRUTH: Contact with persons with albinism **will never** bring bad luck, sickness or death, but IT WILL FOSTER RESPECT, kindness and human dignity.

LIE: One can “catch” albinism like a sickness.

TRUTH: You **cannot “catch” albinism** because it is a genetic condition passed from BOTH parents to children AND ONLY THROUGH BIRTH.

LIE: People can use body parts of persons with albinism to become healed, rich or lucky

TRUTH: No one has or can become lucky or rich or healed from the use of albino body parts.

LIE: People with albinism are a curse or are ghosts and they disappear when they die.

TRUTH: People with albinism are **NOT curses or ghosts** and certainly do **not** disappear when they die. In fact, they are human beings with a simple genetic condition who deserve the same rights that all other Tanzanians enjoy.

- **Ultimate Truth for Teachers and Educators:**

People with albinism are human beings like you. They need care and attention and protection from the sun. They have lower vision levels and need your help in overcoming this challenge in the classroom. With your help they can be very successful students and make significant future contributions to Tanzanian society.

THANK YOU FOR TAKING THESE STEPS!

For more information and support, please contact any of:

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CREDITS

ⁱ Assistance with “Eyes” section came from Dr. Rebecca Kammer, Associate Professor, Eye Care Centre-Southern California College of Optometry. Assistance with “Skin” section came from Dr. John Strasswimmer, Delray Mohs Surgery, Florida. Assistance for “Sensitivity” section came from Donald Sawatzky, MA, Counseling Psychology; General assistance with writing and substance came from Donald Sawatzky, Paul Ash, Vicky Ntetema, Gamariel Mboya, Ikponwosa “I.K.” Ero, Emily, Gremm and the leadership of Peter Ash, Founder and CEO of Under The Same Sun. Primary authors of text, content and layout: Ikponwosa “I.K.” Ero and the Board of Directors of UTSS.

ⁱⁱ **Image of Blackboard from**

<http://www.saddleback.edu/errors/?404;http://www.saddleback.edu:80/itc/user/blackboard/blackboard/blkbdsocccd2.html>

ⁱⁱⁱ **Image of slant desk from** <http://www.visualedgesb.com/about.html>

^{iv} **Large print image from**

http://www.whplibrary.org/newandnoteworthy/2007/05/have_you_tried_a_large_print_b.html; image of hand-held magnifier from <http://www.greenlightoffice.com/office/3/bausch-lomb-handheld-magnifier>; image of monocular from http://www.buffaloloupes.com/loupes/index.php?main_page=index&manufacturers_id=10

^{vi} **Image of shirt from** http://www.info-n-pricing.biz/product_Mountain-Hardwear-Womens-Transit-Long-Sleeve-Shirt.html; Image of hat from <http://www.rei.com/category/5227675?ref=766021>; image of sunscreen from <http://askanesthetician.wordpress.com/2010/01/>.

^{vii} **Image of books from** <http://www.volunteerbc.bc.ca/lle.html>



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