

Solutions: How to Make a Difference (Using Your Attitude)

"Sometimes equality means treating people the same, despite their differences, and sometimes it means treating them as equals by accommodating their differences."

- Judge Rosalie Abella, Report of the Commission on Equality in Employment, Canada

- When a person with albinism (PWA) is being insulted, stand by them!
 - **DO NOT BE SILENT.** As Martin Luther King, Jr. said; "We will remember not the words of our enemies, but the silence of our friends."
 - DON'T STARE when a PWA holds a cell phone or book very close to their face in order to see it. This is due to low vision. While staring is common, it is experienced as rude and disrespectful by a PWA.

• Do not "talk down" to a PWA.

- Be careful not to unintentionally diminish or "talk down to" a PWA. It would be appropriate to say "I am offended by your disrespectful/ignorant behavior!" Do NOT say: "Stop bothering that poor albino."
- If you wish to address a PWA, address him or her directly and not the non-PWA who happens to know him or her.

• Show Respect by what you expect.

 Expect that a PWA can and should function intellectually, socially and, in most cases, vocationally provided that they have been given the same opportunities as others. Create a culture where they know it is safe to tell you when they can't see well enough or when the sun and lighting conditions are too difficult. Minor considerations in these instances will make a significant difference for their success.

• Compel your Government to help.

- Put pressure on your politicians to ensure equality of human rights for PWA in all spheres of life in their country through:
 - Passing relevant laws that protect and care for PWA as persons with disabilities.
 - Enforcing the law once they are passed.

• Get Informed about albinism and spread the word to:

- PWA and their families (many do not understand their own genetic condition);
- Healthcare professionals;
- Teachers and Educators;
- Employers;
- Yourself and society at large.



- Tell Parents, teachers & employers that they MUST:
 - <u>Address low vision challenges</u> for PWA to thrive in home, learning & vocational environments.
 - <u>Protect the skin and eyes</u> when in the sun and avoid direct sun exposure as much as possible. (In Tanzania, between 80 to 90 percent of PWA will die of skin cancer before or by the age of 30 to 40.)
 - See our <u>QUICK GUIDE for TEACHERS</u> if you are a teacher or the parent of a school-aged child with albinism. It is available at: www.underthesamesun.com/resources

Spread the following definition of albinism

ALBINISM – IN A NUTSHELL

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."

- Challenge Myths surrounding albinism with accurate information
 - See attached MYTH BUSTING BROCHURE which addresses commonly held myths in Tanzania. Most cultures have myths of some kind – See ALBINISM AND POPCULTURE at <u>http://www.albinism.org/popcult/</u>
 - **NOTE**:
 - <u>Albinism is NOT contagious</u> Physical touch is perfectly safe.
 - <u>**PWA only have 2 basic vulnerabilities**</u>; low vision and lack of natural protection from the sun due to little or no pigmentation.
 - <u>Albinism is NOT caused by only one parent. BOTH parents</u> <u>MUST understand that BOTH of them DO carry the gene</u> in order to give birth to a child with albinism. **THERE IS NO BLAME** to be attributed.

While there is uniqueness to albinism, persons with albinism bear the image of God just like everyone else.