



## **PERSONS WITH ALBINISM:**

### **A SPECIFIC AND UNIQUE PEOPLE GROUP**

Persons with albinism (PWA) are often easy to spot because they have a pallid appearance that is markedly different from the norm of their race. However, beyond the pale physical appearance and associated disabilities of skin and eyes, PWA are a specific people group primarily because of the myths and supernatural beliefs that are often attributed to them; myths that in actuality, have become a growing threat to their fundamental human rights including their right to life and security of person. Due to the false beliefs specifically attributed to albinism itself, the solution to the problems facing PWA must first begin with identifying them as a specific people group, uniquely targeted due to and because of the mystification of their condition.

- **Unique discrimination peculiar to PWA**

PWA are found in virtually all races, nationalities and cultures of the world, yet they have rarely been given the status of normal human beings. Worldwide, most PWA have been victimized by being viewed as an odd group that do not belong to the mainstream.<sup>1</sup> This undesirable status has resulted in very unfortunate attention and pervasive stigma from their fellow citizens and culture. Most of the stigma-based attention visited upon PWA is maintained by, often unspoken, societal rules.

The stigma of albinism globally has resulted in endemic discrimination against, and death of PWA.<sup>2</sup> It is important to note however that today, PWA are not stigmatized because they have pale skin and low vision issues; but rather because of false beliefs and mystification about the totality of their albinistic condition. These beliefs and myths are centuries-old but continue to thrive. They are present in cultural attitudes and practices around the world. From countries of Africa to

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<sup>1</sup> See image in Appendix, "Albinism Worldwide," photo credit: Positive Exposure, [www.positiveexposure.org](http://www.positiveexposure.org).

<sup>2</sup> While death of PWA due to their condition has been recorded solely in sub Saharan Africa, initial research by Under The Same Sun (UTSS) indicates that infanticide and other types of fatal attacks are also carried out in other countries of Asia. Stigma surrounding albinism was comprehensively chronicled in a radio documentary: "The Imaginary Albino," by Canadian Sociologist, Garth Mullins. First aired on CBC Radio: Ideas, February 18, 2013, CBC Radio: <http://www.cbc.ca/ideas/episodes/2013/02/18/the-imaginary-albino/>, Accessed June 16, 2013.

Asia to North America, albinism conjures a mystical icon in the minds of people – a blank slate<sup>3</sup> upon which fallacies inspired by culture and religion are projected. A growing account of recent reports indicates that these beliefs and myths, which manifest as stigma and discrimination, have increasingly led to the murder of PWA in certain areas.

Therefore the unique qualifier of albinism that warrants the treatment of PWA as a specific people group is *the mystification of their genetic condition itself*. While in some regions of the world this dehumanizing mysticism has resulted in the killing of persons with that condition, it has resulted in stigma, misunderstanding and marginalization in almost all regions of the world. It is this reality, in a contemporary world, that must be given specific attention.

- **Comparative group**

One way of understanding the uniqueness of PWA and the peculiar threat to their human rights as a people group, is through comparison. PWA are very similar to the “untouchables” - the dalit caste of South Asia. Like the dalit, PWA suffer due to the perception, -- religious and cultural -- that others have of them. Further, like the dalit, the result of this perception is stigma and deep discrimination that grossly violates basic human rights.

In addition, for both the PWA and the dalit, there are no real national safety nets because beliefs against them are pervasive and the entire state structure reacts no different than the average person in society. Even where laws exist to protect the victims of these beliefs, those laws are not implemented and the will to implement them remains elusive.<sup>4</sup> The following joint statement on the dalits, issued by seven UN Special Procedures mandate also applies to PWA:

...discrimination remains widespread and deeply rooted, its victims face structural discrimination, marginalization and systematic exclusion, and the level of impunity is very high. ... This form of discrimination entails gross and wide-ranging human rights abuses – including brutal forms of

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<sup>3</sup> See: Urquhart, Emily. “The Meaning of White,” April, 2013, p. 9, *The Walrus*: <http://thewalrus.ca/the-meaning-of-white/>, Accessed March 20, 2013.

<sup>4</sup> See: “UN Welcomes New Law on Caste-Based Discrimination,” May 25, 2011, UN News Centre: <http://www.un.org/apps/news/story.asp?newsid=38496>, Accessed June 16, 2013. Also see “Take Action to Improve Conditions for Dalit Women,” June 7, 2013, Human Rights Watch: <http://www.hrw.org/news/2013/06/07/take-action-improve-conditions-dalit-women>, Accessed June 16, 2013.

violence....Dalit women and girls are particularly vulnerable and are exposed to multiple forms of discrimination and violence, including sexual violence....children victims ...are more at risk to be victims of sale and sexual exploitation.<sup>5</sup>

While the number of dalits in the world are likely in the hundreds of millions, PWA in the world can be estimated to be in the hundreds of thousands.<sup>6</sup> This relatively small number of PWA suggests that their suffering is probably less heard of and less reported. This is a serious issue because it further suggests that some human rights violations against PWA go largely unnoticed. Therefore, treating PWA as a specific group worldwide is necessary to combat the unique challenges this lack of familiarity poses along with the inequities it generates.

- **Specific group identification is the first step to a comprehensive solution**

PWA have more than one actual and potential identity: persons with disabilities, persons with a congenital medical defect, a potential minority group, as well as others. Yet to fixate on any one of these identities will never solve the most pertinent issue facing PWA worldwide: stigma – both chronic and fatal, which targets the purported mystical nature of albinism itself.

Therefore it is important that in bringing an end to the violation of the human rights of PWA; one must avoid reducing albinism to one identifiable aspect such as a disability or a birth defect. While these are valid descriptors of the life experience of most PWA today, they do not reflect the whole of the experience known as albinism and they fail to capture the highest danger facing people with albinism which are the intangible belief system and structures that perpetuate age old fallacies and myths that have had, and continue to have fatal consequences for PWA especially in the region of sub Saharan Africa.

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<sup>5</sup> See: “UN Experts Speak Out on Caste Issue,” May 24, 2013, International Dalit Solidarity Network: <http://idsn.org/news-resources/idsn-news/read/article/un-experts-speak-out-on-caste-issue/128/>, Accessed June 16, 2013. Also see UNICEF and UTSS, “Sexual Abuse Cases Reported in Assessed Schools and Centres Hosting Internally Displaced Children with Albinism and Other Children with Disabilities,” A Report to the Ministry of Education and Vocational Training (MoEVT), May 26, 2011. Also see UTSS’ work on the vulnerability of children with albinism: “Children with Albinism in Africa: Murder Mutilation and Violence: A Report on Tanzania with Parallel References to other Parts of Africa,” A Report to Mme. Santos Pais, UN Special Representative of the Secretary-General on Violence Against Children, June 19, 2012, available at: <http://www.underthesamesun.com/resources>

<sup>6</sup>Albinism occurs in an estimated 1 in 20,000 people in North America and in Europe, however, its occurrence in sub Saharan Africa is far more frequent. Academic research on the frequency tends to place occurrence at an estimated 1 in 1,500. For population of Dalits, see “Dalits,” World Directory of Minority and Indigenous Peoples: <http://www.minorityrights.org/?lid=5652>, Accessed June 16, 2013.

In an ideal world, PWA should not need to be viewed as a specific group who require special attention; and if any attention should be given them, it should be medical. However, and unfortunately, because of the extent of entrenchment of the stigma around PWA, and its fatal consequences in some parts of the world, a holistic understanding of the condition in the context of the mystical reality imputed on PWA is necessary. This is important both for understanding the increasing attacks against PWA and also for finding solutions that will outlast the sometimes fatal, but always dehumanizing, stigma.

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# APPENDIX

**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.

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Photos of individuals with albinism from various countries are shown, including: Canada (David), Puerto Rico (Harry), United Kingdom (Sofia), Cameroon (Ivabelle), Malaysia (Mazlan), China (Brooke), Russia (Dasha), Japan (Ayako), India (Priya), Fiji (Neva), New Zealand (Ciera), Australia (Lauren), Tanzania (Tanzania), South Africa (Sine), Kenya (CK and Daphne), Uganda (Tina), and Brazil (Amanda).