

# APPENDICES

## APPENDIX A: Why We Prefer “Person With Albinism” to “Albino”

### OFFICIAL POSITION OF UTSS

As a group advocating the dignity of persons with albinism, UTSS prefers the term “Person with Albinism (PWA)” and its similar variants over the term “albino.”

This is not only because of the historically derogatory use of “albino,” but also because the term, PWA, puts the person before their condition.

That said, we understand that the world is currently in transition from the use of “albino” to PWA hence, in some rare instances, we might be forced to use albino if the use of PWA compromises a relevant and important message being conveyed.

### REASONS FOR OUR POSITION

- **Albino**
  - **Albino is a word that captures both a person and her condition**
  - **Therefore to use the word albino is to equate the person to her most visible aspect: albinism**
  - **This equation of person with visible condition is contrary to global efforts to advance the humanity and dignity of *all* persons**

#### REFLECTIONS ON ALBINISM

“Albinism is etched in our imagination, yet the condition is rare enough in daily life that it has no human face. We carry the condition; the world carries its weight and meaning. Such deep-set words are hard to extract. Still, it’s hard sometimes not to resent albinism’s role as one of the last unmitigated means to marginalize and ridicule, especially as we are so swift to parse out people from their condition. It’s no longer “Idiot Savant,” it’s Savant Syndrome, not “Siamese twins,” but conjoined. Not “albino,” therefore, but person with albinism. In the beginning was the word. It’s still here. One day, education will dispel ignorance and decency drive it out altogether. Until then, please refer to my condition, and use my name.”

ANDREW LEIBS

WRITER AND PERSON WITH ALBINISM

## APPENDIX B: About Under The Same Sun

UTSS Fund exists to promote, via advocacy and education, the wellbeing of persons often marginalized and misunderstood. Specifically, we focus on those who are disadvantaged by disability and/or poverty. At UTSS, we are driven by the belief that all persons have intrinsic value as each is created in God's Image. Accordingly, we also believe that all persons are worthy of love, respect and true dignity.

### VISION

That the day will come when PWA in Tanzania and Africa will take their rightful place in all aspects of society and that the days of discrimination will be a faint memory.

### KEY PROGRAMS

2 well-staffed departments. Over half of our members of staff are PWA

#### **Education Scholarship Fund (ESF)**

Offers grants to children and adults with albinism at all levels of education and in many regions of Tanzania. Our grantees are placed in the best and safest educational environments that Tanzania has to offer.

#### **Advocacy and Public Awareness (APA)**

APA uses a variety of media to educate the public on albinism. It also conducts specific programs to diffuse existing myths that often lead to discrimination and justify macabre killings.

### SOME HIGHLIGHTS OF OUR WORK

- **Over 300 students on our Education Scholarship Fund Program**  
Students in our ESF program range from primary to PhD levels
- **Our Documentary on albinism titled *White and Black: Crimes of Colour*** has been widely viewed in Africa through community screenings – outdoor and indoor.

- **Frequent Low Vision Clinics** run by Dr. Rebecca L. Kammer, an Associate Professor of optometry and low vision at the Southern California College of Optometry in Anaheim, California. These have served our ESF grantees and staff with albinism. Low vision gadgets are also provided at no cost.

## APPENDIX C: Detailed Record of Killings (CONFIDENTIAL)

As of June 19 2012

### CONFIDENTIAL RECORD



### MURDERED PWA IN TANZANIA (Recorded Cases Only)

2008 TO DATE

Last updated

10/06/2012

#	PERSONAL INFORMATION				SOURCE		LOCATION
	NAME	AGE	GENDER	DATE	INFORMANT	REGION	
1	Arodia	Augustino	16	F	2008-12-03	Tz Police	n.a.
2	Solomon	Laurian	28	M	2009-01-17	Tz Police	n.a.
3	Michael	Petro	6	M	2009-01-14	Tz Police	Kagera
4	Sauda	Ibrahim	20	F	2008-09-03	Tz Police	Kagera
5	Rebecca	Machungwa	10	F	2008-11-17	Tz Police	Mwanza
6	Magdalena	Andrew	30	F	2008-09-21	Tz Police	Kagera
7	Jovin	Majaliwa	46	M	2008-07-25	Tz Police	Kagera
8	Nyerere, Rutalilo	Ludayila	50	M	01/07/2008	Tz Police	Mwanza
9	Zawadi	Magidu	22	F	2008-03-11	Tz Police	Mwanza
10	Vumilia	Makoye	17	F	2008-05-17	Tz Police	Mwanza
11	Eunicy	Bahati	12	F	2009-02-17	Tz Police	Mwanza
12	Aaron	Nongo	45	M	2009-06-26	Tz Police	Mwanza
13	Jesca	Charles	21	F	2009-06-21	Tz Police	Mwanza
14	Rwegamoyo	Kilanga	65	M	2007-10-03	Tz Police	Mwanza
15	Mariam	Emmanuel	5	F	2008-01-21	Tz Police	Mwanza
16	Naimana	Daudi	4	F	2010-04-18	Tz Police	Kigoma
17	Gaspar	Elkana	10	M	2009-10-21	Tz Police	Mwanza
18	Waziha	Balyehele	9	F	2008-02-01	Tz Police	Mwanza
19	Jonas	Maduka	48	M	2009-01-22	Tz Police	Mwanza
20	Esther	Charles	9	F	2007-10-19	Tz Police	Shinyanga
21	Matatizo	Dunia	10	M	2008-12-01	Tz Police	Shinyanga
22	Ng wama	Kimbichi	65	F	2008-03-11	Tz Police	Geita
23	Amon	Ariph	35	M	2006-04-17	Tz Police	Mwanza
24	Shitakelewelwa	erwa	45	F	2007-05-23	Tz Police	Mwanza
25	Mabala	Silas	12	M	2007-11-17	Tz Police	Mwanza
26	Kija Maracu/Mariam	Mbogo	0.6	M	2008-07-11	Tz Police	Shinyanga
27	Henry	Mwakajila	17	M	2008-02-05	Tz Police	Mbeya
28	Japheti	Kaliita	28	M	2009-01-16	Tz Police	Kagera

29	Sifa	Yuvenary	5	F	2008-11-24	Tz Police	Kigoma
30	Lyaku	Wille	54	M	2009-12-06	Tz Police	Shinyanga
31	Kulwa	Gilibha	7	F	2009-07-02	Tz Police	Tabora
32	Nyamiti	Nyamakanya	33	F	2008-04-21	Tz Police	Mara
33	Winfrida Giayati	Oluoch	22	F	2008-03-03	Tz Police	Mara
34	Zacharia	John	40	M	2008-12-03	Tz Police	Kigoma
35	Ibrahim	Shabani	45	M	2008-11-17	Tz Police	Mwanza
36	Muhanda	Sitta	4	M	2008-07-23	Tz Police	Shinyanga
37	Juma	Singisha	46	M	2009-06-24	Tz Police	Mara
38	Ezekiel	John	47	M	2008-12-04	Tz Police	Kigoma
39	Remy	Juma	12	F	2007-08-15	Tz Police	Mwanza
40	Zacharia	Juma	7	M	2007-08-15	Tz Police	Mwanza
41	Veronica	Ghati	26	F	2008-01-08	Tz Police	Mwanza
42	Unknown	Unknown	1.7	n.a.	2008-09-00	Tz Police	n.a.
43	Unknown	Unknown	n.a.	M	2009-03-05	Tz Police	n.a.
44	Unknown	Unknown	n.a.	M	2009-10-13	Tz Police	n.a.
45	Unknown	Unknown	n.a.	F	2008-08-14	Tz Police	n.a.
46	Unknown	Unknown	n.a.	n.a.	n.a.	Tz Police	n.a.
47	Unknown	Unknown	n.a.	n.a.	n.a.	Tz Police	n.a.
48	Unknown	Unknown	n.a.	n.a.	n.a.	Tz Police	n.a.
49	Unknown	Unknown	n.a.	n.a.	n.a.	Tz Police	n.a.
50	Unknown	Unknown	n.a.	n.a.	n.a.	Tz Police	n.a.
51	Unknown	Unknown	n.a.	n.a.	n.a.	Tz Police	n.a.
52	Unknown	Unknown	n.a.	n.a.	n.a.	Tz Police	n.a.
53	Unknown	Unknown	n.a.	n.a.	n.a.	Tz Police	n.a.
54	Unknown	Unknown	n.a.	n.a.	n.a.	Tz Police	n.a.
55	Unknown	Unknown	n.a.	n.a.	n.a.	Tz Police	n.a.
56	Unknown	Unknown	n.a.	n.a.	n.a.	Tz Police	n.a.
57	Unknown	Unknown	n.a.	n.a.	n.a.	Tz Police	n.a.
58	Noela	Neema	0.42	F	2010-12-31	Tz Police	Kagera
59	Rosemary	Mathayo	16	F	2000-00-00	UTSS	Kagera
60	Pracseda	Mathayo	14	F	2000-00-00	UTSS	Kagera
61	Focus	Mathayo	4	M	2000-00-00	UTSS	Kagera
62	Doto	Mbiti	1.2	M	2011-05-13	UTSS	Geita

63	Juma	Mgendi	46	M	2009-06-24	UTSS	Musoma
64	Kulwa Tabu	Elias	3	F	0000-00-00	Tz Police	n.a.
65	Nhandi	Peter	4	F	n.a.	Tz Police	Mwanza
66	Nyamanoko	Daudi	16	F	2007-11-17	Tz Police	Mara
67	Amos Musa	Malongo	5	M	2008-00-00	UTSS	Shinyanga
68	Elizabeth	Hussein	13	F	2008-12-00	Tz Police	Shinyanga
69	Minza	Mugema	10	F	2007-10-04	Tz Police	Mara
70	Nyamatondo	Unknown		F	2008-00-00	UTSS	
71	Unkown	Unknown	25	M	2012-05-22	TAS	Arusha
<b>TOTAL OF DOCUMENTED MURDERS</b>			<b>71</b>				

*Note: List of Survivors and Grave Robberies are not included here but are available upon request/*

## APPENDIX D: A Sampling of Centres Holding Internally Displaced Children with albinism

### A SAMPLING OF CENTRES HOLDING INTERNALLY DISPLACED CHILDREN WITH ALBINISM

CENTRES HOLDING DISPLACED PWA	TOTAL	PWAC	%
Buhangija primary school, Shinyanga	812	79	10
Bukumbi Centre for the Elderly and Vulnerable	368	10	3
Furaha School for the Blind, Tabora	92	16	17
Kabanga Primary School, Kigoma	883	74	8
Kitengule Primary School, Kagera	243	12	5
Missionaries of Charity, Tabora	134	20	15
Mitindo Primary School, Mwanza	1172	103	9
Mugeza Mseto Primary School, Kagera	174	33	19
Pongwe Primary School, Tanga	1058	29	3
<b>TOTALS</b>	<b>4936</b>	<b>376</b>	<b>8</b>

#### KEY

TOTAL	Total number of children at the centre including children who are PWA
PWAC	PWA children at the centre
%	PWAC as a percentage of TOTAL

Data extrapolated by UTSS from the following report:

**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)**  
**26-May-11**  
**Under The Same Sun / UNICEF**  
**NOTE: Report covers only children with albinism**

Preliminary findings from this report also disclosed frequent sexual abuse of children

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## **APPENDIX E: Bodies that appear to serve PWA in Tanzania and Africa**

### **Tanzania**

#### **Good Hope Star Foundation**

Headed by Tanzania Member of Parliament, Mme. Alshaymaa Kweygir

#### **Barwani Albino Development Fund (BADF)**

Headed by Tanzania Member of Parliament representing the Constituency of Lindi, Mr. Salum Khalfhani Barwani

#### **Ocean Road Hospital, Dar es Salaam**

This is one of the most common hospitals for the treatment of PWA who have developed skin cancers. The hospital is largely government run and provides the cancer treatment at little or no cost to PWA.

#### **Regional Dermatology Training Centre (RDTC)**

Located in Kilimanjaro, it is the only centre with comprehensive care facilities for both visual and skin aspects of albinism. The Centre has foreign donors and human resources as well as local staff. Trained personnel provide both skin cancer treatment and low vision assessment. The Centre is about to launch local sun production Unit.

#### **Tanzania Albino Society (TAS)**

TAS strives to emancipate albinos in Tanzania and Africa as a whole from society's negative attitude, discrimination, stigma and humiliation by overcoming barriers that hinder them from enjoying human rights. From [www.tanzaniaalbinosociety.org](http://www.tanzaniaalbinosociety.org) (March 29, 2012)

#### **Under The Same Sun (UTSS)**

Full details available at Appendix B



## Rest of Africa

Senegal	West Africa	People with albinism in Senegal
Cameroon	West Africa	Association mondiale pour la défense des intérêts et la solidarité des albinos (ASMODISA)
Zimbabwe	Southern Africa	Zimbabwe Albino Association
Mali	West Africa	Salif Keita Global Foundation
Ghana	West Africa	Ghana Association of Persons with Albinism (GAPA)
Tanzania	East Africa	The Albino Society (TAS)
Burkina Faso	West Africa	Association nationale pour l'intégration des personnes albinos (ANIPA)
Nigeria	West Africa	The Albino Foundation
Kenya	East Africa	Albinism Society of Kenya (ASK)
UK/Nigeria	Europe	Albino Network Association of Nigeria
US/Tanzania	North America	Asante Mariammu
South Africa	Southern Africa	Albinism Society of South Africa (ASSA)
Congo (Brazzaville)	Central Africa	SOS Enfants Vulnérables Sans Frontières
Central African Republic (CAR)	Central Africa	Association Nationale des albinos de Centrafrique (ANACA)
Democratic Republic of the Congo (DRC/RDC)	Central Africa	Action pour la protection et l'intégration des personnes albinos (APIDA)

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Democratic Republic of the Congo (DRC/RDC)	Central Africa	Association pour la Promotion et le Développement de la Personne Albinos (APRODEPA)
Democratic Republic of the Congo (DRC/RDC)	Central Africa	Albinos Sans Frontières
Benin	West Africa	Association des Hommes de bonnes Volontés pour le Développement
Senegal	West Africa	Association Nationale des albinos du Sénégal (ANAS)
Senegal	West Africa	Alliance Nationale pour la Promotion à la Réinsertion des Albinos au Sénégal (ANPRAS)
Togo	West Africa	Cercle d'Entraide aux Albinos Malvoyants (CEAM)
Uganda	East Africa	Uganda Albinos Association



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