Understanding Albinism and
its challenges to people
with albinism

August 2015
WHAT IS ALBINISM?

• Albinism is lack of pigmentation in the body affecting the skin, eyes and hair.

• It is a rare condition, genetically inherited from both parents – (the father and the mother);

• it is a non-communicable condition, occurring on both genders, in all countries of the world regardless of ethnicity, and it also found in all living things.

• Due to lack of pigmentation in the skin, hair, and eyes, PWA are vulnerable to sunrays and bright light.
What is albinism? Cont....

- Almost all people with albinism are **visually impaired**. That is the disability element in albinism. In North America persons with albinism are regarded legally blind.

- In North America and Europe, it is estimated that - 1 in every 20,000 people has some form of albinism, while in Tanzania and East Africa - 1 in 1,400 people are affected.
Albinism is Worldwide
Albinism is in all living things
HOW DOES A PERSON BECOME A PWA?

- Both parents of a PWA, whether they have albinism or not, must carry the genetic trait of albinism before a child with albinism can be born.
- (25%) chance at each pregnancy that the baby will be born with albinism.
- Normal pigmented children born to such parents also carry the genetic trait for albinism.
TYPES OF ALBINISM

• Albinism only effecting the eyes. This is called Ocular albinism (OA), and is much less common. Most cases are ocured in males. May have skin and hair color that are normal.

• Albinism affecting the skin, hair and eyes. This is known as Oculocutaneous Albinism (OCA). This is the most visible form of albinism.

• OCA Albinism has also four forms are now recognized – OCA1, OCA2, OCA3 and OCA4; some of these are further divided into subtypes. In each the degree of colour apparent in the individual varies slightly.

• Hermansky-Pudlak Syndrome (HPS): In addition to having albinism, people with HPS have bleeding problems, bruising lung and bowel disease.
4 MAJOR CHALLENGES FACE PWA

- LOW VISION
- RISK OF SKIN CANCER
- MAJOR SOCIAL EXCLUSION/REJECTION
- THREATS AND ATTACKS
- LACK OF ACCURATE INFORMATION ABOUT ALBINISM
1. LOW VISION
LOW VISION

• PWA have low vision simply especially in a bright light. This is because the eye fail to regulate the amount of light entering the eye.

• Low vision negatively affects educational performance of most persons with albinism in Tanzania.

• Most of education providers do not know this challenge and how to overcome.
RISK OF SKIN CANCER

- There is little or no skin pigment on a person with albinism and, hence, no protection from sun damage.
- Many Tanzanians with albinism die of skin cancer before the age of 40.
- The sunrays damage the skin and there is no proper medication except in two referral hospitals of Kilimanjaro Christian Medical Center (KCMC) of Moshi Kilimanjaro and the Ocean Road Cancer Institute (ORCI) of Dar es Salaam to which majority of persons with albinism cannot reach
WARNING!!!

THE FOLLOWING SLIDES CONTAIN IMAGES OF AN EXTREMELY GRAPHIC NATURE
RISK OF SKIN CANCER
In Africa, most PWA die by age 40
MAJOR SOCIAL EXCLUSION/REJECTION

• Mystification
• Global Stigma
• Discrimination

=  

• Human Rights Violations
THE SPECTRUM OF STIGMA/DISCRIMINATION

Names used for PWA 70% are dehumanizing and 30% are NON/DE-HUMANIZING

``ALBINO`` VARIANTS
- Ghost (Australia & more)
- White monster (Tanzania)
- Freak (Canada)
- Money (Kenya)
- The Devil in person (Haiti)
- Ape (South Africa)
- Goddess of the Waters (Nigeria & CAR)
- Albino (Canada)
- Bianca (France)
- Beano (Australia)
LACK OF ACCURATE INFORMATION ABOUT ALBINISM

• Most of people have no proper information about albinism. The result of this situation is rejection caused by lies from myths which holds that persons with albinism are

➤ ghost and a curse;

➤ that their organs can bring prosperity, money/success;

➤ that they don’t die but disappear;
LACK OF ACCURATE INFORMATION ABOUT ALBINISM CONTINUATION

- that wounds on their bodies are a natural phenomenon;
- that if raped can cleanse and cure Sexually-Transmitted diseases, HIV and AIDS.
- Midwives lack knowledge about albinism hence do not counsel mothers when they have babies with albinism
LACK OF ACCURATE INFORMATION ABOUT ALBINISM Cont

• Parents leave their CWA in the sun hoping that they would “get darker”

Knowing the truth about albinism will automatically reduce such negative attitudes and social practices against persons with albinism.
STIGMA/DISCRIMINATION AND LACK OF ACCURATE INFORMATION ABOUT ALBINISM COMBINATION

• Stigma/discrimination and lack of accurate information causes Dehumanization to people with Albinism.

• Dehumanization lays the foundation for witchcraft attacks. Which includes;
  - Abduction
  - Mutilation
  - Murder
  - Rape
  - Grave robberies
  - Trafficking in PWA organs
THREATS AND ATTACKS

• The situation at this time is even worse to the extent that the positive image of our mother country Tanzania also known as the Island of peace is bad. Many persons with albinism have been brutally murdered, mutilated, kidnapped and some of their graves have been robbed in search their body parts for superstitious activities.
WARNING!!

THE FOLLOWING SLIDES CONTAIN IMAGES OF AN EXTREMELY GRAPHIC NATURE: ATTACKS ON CHILDREN
7 year old Lugolola Bunzari, killed January 31, 2013 in Tanzania

18 year old Chantal Ngendakumana, killed May 6, 2012 in Burundi
12-year old Adam Robert, attacked October 14, 2011 in Tanzania
7 month old Mariamu Kija Mbogo, killed July 11, 2008 in Tanzania

5 year old Mariamu Emmanuel, killed January 21, 2008 in Tanzania
SOLUTION TOWARDS SUN SENSITIVITY CHALLENGES

• Protective Gear:
  o Long-sleeved clothes
  o Wide-brimmed hats
  o UBV Sunglasses
  ▪ Avoid sun exposure
SOLUTION TOWARDS SUN SENSITIVITY CHALLENGES cont

- SPF +30 sun lotion must be freely available.
- Student intake of medical doctors and nurses should include persons with albinism.
- Access to Free and Regular (monthly) dermatological services to detect skin cancer
- Specialized dermatology medical training should include albinism because of its prevalence in the country.
SOLUTION TOWARDS SUN SENSITIVITY CHALLENGES cont

• Public education on protection through appropriate clothing, use of sun screen lotion and spread of dermatologic services to regional and district hospitals may be part of the solution.

• **Cryotherapy** is needed to treat lesions as early staged of skin cancer. Cylinders for storing and transporting liquid nitrogen have to be purchased for every district. Tanzania produces liquid nitrogen in plentiful.
LOW VISION SOLUTIONS

• Blackboard & White Chalk
• Large Fonts and Print
• Speak as You Write
• Notes for SWA prior to class
• SWA - near the board
• Team SWA with peers without albinism
SOLUTIONS ON HUMAN VIOLATION.

• Statistics: An independent census should be conducted by a private company.

• Concerning myths: National-wide Advocacy and Public Awareness Campaign. This should be done in every sections eg; In Health section, in learning institutions etc.

• More have to be discussed during discussion section
Election Years Attacks  
2014 - 2015

• **Abductions:**
  
  • December 27, 2014: Pendo Emmanuel (4) was abducted in Kwimba District. Pendo is still missing – presumed killed.
  
  • January 15, 2015: Yohana Bahati (1) was abducted in Ilelema Village, Chato District
  
  • June 16, 2015: Margreth Hamis (6) was abducted and later rescued from the hands of her kidnaper (her uncle), Masanja Mwinamila (44) in Tabora.
Election Years Attacks
2014 – 2015 cont

Killings:

• May 12, 2014: Munghu Lugata (40) in Simiyu, Mwakalala in Bariadi, Simiyu Region.

• January 17, 2025: Yohana Bahati (1) mutilated body was found about 10 km from his home village in Katoro, Geita Region.
Election Years Attacks 2014 – 2015 cont

Mutilations:

• August 5, 2014: Pendo Sengerema (15) lost her right arm in Urambo.

• August 14, 2014: A body of a man with albinism was found mutilated in Kinyerezi, the outskirts of Dar es Salaam.

• August 16, 2014: Munghu Masaga (35) was attacked and her left severed arm in Buhekela, Igunga March 7, 2015:
Election Years Attacks
2014 – 2015 cont

Mutilations

• March 6, 2015: Baraka Cosmas Rusambo (6) was attacked and his right hand hacked off in Rukwa Region.

• May 14, 2015: Limi Luchoma (30) was attacked and her right arm cut off in Kabunde, Katavi.
Swaziland’s albinos have called on the government for protection ahead of elections expected later this year, fearing their body parts will be harvested by candidates seeking good luck.

“Those in authority must make sure that our safety is guaranteed,” Skhumbuzo Mndvoti, an albino community leader living in the southern town of Nhlangano told AFP.

“I can warn both adults and parents of albino children to take extra care during these election days,” Mndvoti said.

Ritual killings are common of in Swaziland, and elsewhere in Africa, with “muti” practitioners -- a catch-all for traditional medicine and witchcraft -- using limbs or body parts as amulets.

Full story available at: http://www.nation.co.ke/News/world/Swazi-albinos-plead-for-protection-ahead-of-vote/-/1068/1861356/-/item/1/-/blp9q0z/-/index.html
‘Politicians killing albinos

The government admitted yesterday that politicians could be behind increased attacks and killings of people with albinism in the country.

The accusation came in the wake of reports that linked the country’s political power pursuit with attacks on albinos because such incidents rise during elections time.

It is erroneously believed that the body parts of persons with albinism bring fortune, and thus some politicians seek them ostensibly to boost their chances of winning in the polls.

In March, the UN condemned the wave of albino killings in Tanzania, warning that the upsurge could be linked to the forthcoming General Election campaigns.

Speaking in Geneva, the UN High Commissioner for Human Rights, Mr Zeid Ra’ad al Hussein, warned that the surge could be linked to the looming General Election in October this year, as power aspirants may be turning to sorcerers to boost the chances.

He noted that in the past six months, at least 15 people with albinism in Tanzania, Malawi and Burundi have been abducted, wounded, killed or escaped being kidnapped, including three such attacks in the past week alone.

Deputy Minister for Home Affairs, Mr. Pereira Silima, yesterday told the Parliament that he also had heard of the reports linking politicians with the killings of people with albinism.

“This could be true because the killings are increasing during elections,” he said.
Passed Bills, Resolutions & Reports Condemned Killing of PWA

- EU Bill on the killing of albinos in Tanzania
- US House Resolution 1088
- Canadian House of Commons Motion
- UN Resolution L25
- UN Resolution L36
- African Union Resolution 263
- UN Resolution L35
- Report of UN Human Rights Council Advisory Committee on The Human Rights of PWA
- UN Resolution L10
Recommendation

• Social practitioner have to interfere on this and pray a role in ending discrimination, stigma and atrocities.

• The government of Tanzania, as a nation, has to work hard to restore peace and tranquility to all citizens including persons with albinism,

• The government has to announce the on-going murders, mutilations and kidnapping of persons with albinism as a national disaster so that every stakeholder is involved in seeking for an everlasting solution.

• The Parliament of Tanzania has to, strategically take this problem as an agenda for discussion and finally advice the government on how best they can solve the problem.

• Public education on “Understanding Albinism” must be an endless agenda for the media so as to do away with the existing negative attitudes against persons with albinism in Tanzania.
LET’S BUILD A TANZANIA WITHOUT PWA ATROCITIES!
LET’S DECLARE TODAY!

• Let’s take the lead! Let’s declare today that Tanzania which was the first country in the world to admit that these atrocities were being committed would now be the first nation to end these inhumane attacks against our brothers and sisters with albinism! I know we can!

• Together we can change the mindsets of Tanzanians about albinism and if we apply equal opportunity policy and positive discrimination for PWA! Let’s us realize the dream that one day in Tanzania and Africa persons with albinism will take their rightful place in every level of the society and days of discrimination, stigma and atrocities against PWA will be a faint memory!
Thank you for listening
FOR MORE INFORMATION

Please contact:
UNDER THE SAME SUN
Taasisi Road, Mikocheni B, Kwa Warioba
Box 32837, Dar es Salaam

vicky@utss.co.tz; heviado35@gmail.com
Info@utss.co.tz

Email: info@underthesamesun.com
Web: www.underthesamesun.com
www.facebook.com/underthesamesun