The Human Rights Situation of Persons with Albinism:

A Crisis and An Opportunity

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26 October 2017
New York, NY
Background

- 600 +
- Reported cases
- 28 Countries – Most recent this month
- Types of attacks
  - Witchcraft
  - Trafficking
  - Organized Crime
  - Children
Outline

- What is albinism?
- The Situation
- Current Initiatives and Your Role
What is albinism?

- A relatively rare genetically inherited difference occurring in both genders regardless of race, in all countries of the world.

- Results in a lack of pigmentation in the hair, skin and eyes, causing vulnerability to sun exposure and bright light.

Rates:

- North America / Europe: 1 in 17,000 people.
- Africa: 1 in 5,000 to 1 in 15,000 with estimates as high as 1 in 1,000 in some groups (WHO)

- Term “person with albinism” (PWA) is preferred to the term “albino”.
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.
HOW

• Both parents of **must** carry the genetic trait of albinism – even when neither have albinism

• **25% chance** at each pregnancy that baby will have albinism.

• Normal pigmented children born to such parents may carry genetic trait for albinism.
TYPES

• Albinism affecting eyes only. This is called Ocular albinism (OA) – males mostly

• Albinism affecting the skin, hair and eyes.
  • “Oculocutaneous (OCA)”
  • (Most visible)

• Hermansky-Pudlak Syndrome (HPS): albinism plus bruising lung and bowel disease.
Brothers with and without albinism from North America. He has OCA Type 1

African with OCA Type 2
Low Vision

- Low Vision - 20/200 vision
- Glasses - assistive not corrective
- Varying degrees in each PwA
- Photophobia
- Adaptive gadgets ARE KEY
  - Monocular
  - High-Prescription Glasses
  - Magnifiers
  - Sun glasses etc
Skin Cancer

- Highest Killer
- Only 2% live beyond age 40
- Preventable with
  - Info
  - Avoidance habits
  - Protective Clothing
  - Sunscreen
- Cure e.g. Chemo is rare
- Lesions add Stigma
- Fuels Myths

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Skin Cancer
Discrimination

- **On SPECTRUM. ON ONE END....**
- No positive/accurate portrayal of PWA in the arts, literature and media.
  - villains, demons, ghosts, freaks of nature, mystical anomalies, village idiots, in a majority of films in the last 50 years +
Discrimination

ON ONE END Contd....

- NON/DE-HUMANIZING
  - Ghost (Australia & more)
  - White monster (Tanzania)
  - Freak (Canada)
  - Money (Kenya)
  - The Devil in person (Haiti)
  - Ape (South Africa)
  - Goddess of the Waters (Nigeria & C.A.R.)

- `ALBINO` VARIANTS
  - Albino (Canada)
  - Bianca (France)
  - Beano (Australia)
Discrimination – on the other end
Structural and Systemic
Birth
- Many killed at birth. "white" skin to dark parents is a curse & shame

Education
- Low Vision leads to high dropout rates

Employment
- Work in the sun due to low education for indoor jobs

Poverty
- Low education and low skill consign PWA to poverty

Skin Cancer
- Work in the sun and absence of health education

Death
- Skin cancer kills most PWA before age 40
Outside Africa

- China
- India, Spain
- Dark pop’n > Stigma
- Skin Cancer
Discrimination – on the other end
Attacks and Violence

Warning: Photos are graphic. Shown to honour dead and bring end to attacks
Reported Attacks

- Benin: 12
- Botswana: 3
- Burkina Faso: 9
- Burundi: 39
- Cameroon: 11
- DRC: 67
- Egypt: 1 (Asylum)
- Ghana: 3
- Guinea: 15
- Ivory Coast: 30
- Kenya: 13
- Lesotho: 1
- Malawi: 113+
- Mali: 15
- Mozambique: 68+
- Namibia: 3
- Niger: 1
- Nigeria: 10
- Rwanda: 1
- Senegal: 9 (incl. 2 asylum)
- South Africa: 8
- Swaziland: 11
- Tanzania: 176
- Togo: 1
- Uganda: 8
- Zambia: 9
- Zimbabwe: 2
Record of Attacks

- **Most recent attack:** three countries this month
  Countless uncovered, likely in many other nations.

- “...muti activities are often shrouded by a **code of silence** which makes reporting, and the necessary prosecution and investigation all the more difficult.”

Root causes

- Ignorance on albinism
- Myths
- Poverty – BUT not really
- Capitalism / Get-rich-quick
- Corrupt or/ & ill-equipped system
- Burden of albinism
- Witchcraft practice
  - WHAT exactly is witchcraft?
Prosecution

- 0-50% est
- Death penalty debate
Displacement

• Impossible to tell exactly but it is “certain that thousands have been displaced.” IFRC
• - “Small scale humanitarian crisis”
• ONGOING:
• Certain “overwhelming majority not free to move around, work or farm”
• Hundreds still displaced
CURRENT ACTION – IE

- Country VISIT
  - PWA directly
  - Parents of PWA
  - Govt
  - Witchdoctors
  - Prisoners
- Reports
- Advocacy
- Remove barriers to enjoyment of HR
CURRENT ACTIONS- IE

- Intersectional approach
  - Disability, Health, Colour/Racial disc.
  - Torture, Refugee
  - Harmful Practices, Witchcraft, Traffick*
  - Women and Children
- Multi-sectorial implementers
- Specific Measures***KEY
REGIONAL ACTION PLAN ADOPTED

- Adopted at the ACHPR – May 2017 – Milestone !!!
- 15 Specific Measures (2017 - 2021)
- 4 clusters – Protection, Prevention, Acct, Non Disc
Regional Action Plan
Cont`d

- **Specific measures include:**
  - community protection
    - CBM Guidelines
  - Healthcare workers – TRAIN
  - Graveyard Protection
  - Witchcraft Legislation
  - Trafficking Legislation
  - Criminal law e.g. sentencing guidelines
  - Mastermind – Investigation
  - Public education – innovative ways
Regional Action Plan

- WHY:
  - Exact violence is regional
  - African response
  - New approach / implementation issue
  - Urgent response
  - Dynamic of aid
Regional Action Plan

- **STRATEGY:**
  - Instigate national plans
  - Standardize and measure
  - Coordination platform
  - Organizations with passion and regional capacity
  - Bring in Foundations
  - IE Coords with govt
  - Pretoria: first strategy meeting
Regional Action Plan

• MODALITIES:
  • Website -- Coordination Platform
    • Map - ongoing work
    • Monitoring and Evaluation
    • Implementation Gaps
  • Resources: Best Practices – Plans, laws, Projects, HR Edu
  • Progress reports
  • Fundraise and Resources
Regional Action Plan

- WILL IT WORK?.... YES!!!
- Components are successful
- Scale up opportunity
- Coordination of effort
- Govt investment
- Speed up response
- New approach: not waiting for State as primary duty bearer
Regional Action Plan

YOUR ROLE:

• Break Silos. Break aid determinism
• Respond to Pressing Issue
• Be part of a new approach to int'l HR implementation
• Part of collaboration
• Support the collaboration
• observe in Pretoria
• Follow Up
Why Should you Care?

- SDG–Agenda 2030: “Leaving no one behind. Starting with the furthest behind first”
- Possibility of real change
  - Small number
  - Pilots – high success
Reality Check:

- Some things will take longer:
  - Witchcraft
  - Demystification
Real Change -
Conclusion

“Leaving No One Behind.... Beginning with the furthest behind first.”

--- UN SDG Agenda2030

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