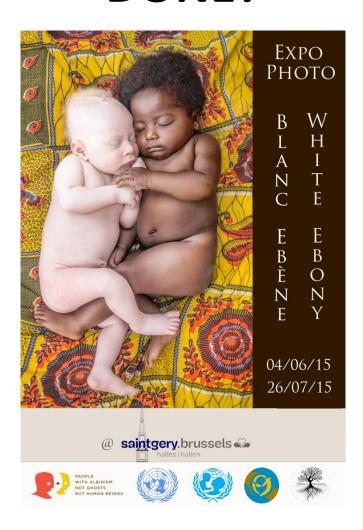
INTERNATIONAL CONFERENCE ON RARE DISEASES (RAREX) 2016 CAPE TOWN SOUTH AFRICA

ALBINISM: STIGMA WHAT CAN BE DONE?
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BIOMEDICAL INFORMATION

- ALBINISM is an inherited genetic condition due to the failure of the human body to produce melanin. A person with albinism will then be born with little or no pigment in the eyes, hair and skin.
- Someone with albinism is commonly referred as an "albino" a pejorative term referring a white skinned person. Consequently, a person is labelled as different from his community due to the colour of skin.
- The term "albino" comes from latin "albus" = white and was used similarly to "Negro" from latin "niger" = black for the black population of antiquity. While the latter term is now deemed an offensive term to describe black population, the former is still used to describe a person with albinism.

- BIOMEDICAL INFORMATION CONTINUED...
- Just a labelling of a person with albinism is in itself a source of stigma to the family and parents. A child born with less or no pigment is look different to his family and community who are not aware of types of albinism.

TYPES OF ALBINISM

- Generally parents are not aware till they give birth to a child with albinism.
- Oculocuteneous Albinism and Ocular Albinism
- Firstly, oculocuteneous albinism is a type of albinism that affects skin, hair and eyes. It is obvious type of albinism as a person will look pale or white then different from his parents or community.

- TYPES OF ALBINISM CONTINUED...
- Secondly, ocular albinism is albinism that
 affects only the eyes. The skin is pigmented or
 normal colour. There is a probability to give
 birth to a child with albinism. Both parents
 need to carry the gene of albinism.

• BELIEFS AND SUPERSTITIONS LEADING TO TRAUMA

- Persons with Albinism don't die, they just dissappear
- Mother had an affair with a white male, hence the white baby
- Persons with Albinism have special powers that bring luck
- They are a curse to the family
- Offensive name calling (i.e Monkey, Phantom, Ghost, Snow)

- Suggestions to alleviate trauma arising from stigma:
- Education and Awareness campaigns in local communities, health sector, schools through NGO sector
- Development of clear government policy on access to social grants
- Promotion of acceptance in the family
- Recognition of the condition of Albinism as a Disability in terms of CRDP
- Need of academic programme on the genetic condition of albinism. For instance, life orientation course should include albinism as subject or chapter at primary, secondary high schools to educate future leaders of the country or potential parents

THE END

THANK YOU