Problems and Challenges of Vitiligo in Africa

Recognition of Vitiligo as a neglected or orphan disease by Health System
My Country Health System is yet recognize Vitiligo as anything from neglected to rare or chronic condition, presently there is no classification whatsoever, only the Dermatology unit of the University Teaching Hospitals, Medical Centers and a few private skin clinics atleast has knowledge of vitiligo. It is totally neglected and underestimated in Africa, usually termed cosmetic and not life-threatening. In the Health Ministries, there is no section for skin diseases/conditions let alone vitiligo.

Problems being faced by Individuals living with vitiligo and vitiligo organizations'/support groups in Africa cannot be complete without in-depth sharing of the cultural Beliefs and the challenges of those in the rural and urban areas.

Beliefs:
Vitiligo is a hugely stigmatised condition, especially in Africa. Facing not only a visible, disfiguring skin problem, many patients also endure psychological, psychosocial and emotional stress from the condition and its stigma. This usually results in increased susceptibility to vitiligo: the stress of stigmatisation can often lead to further progression of Vitiligo.
Social, religious and tribal factors play a significant role in stigmatisation in Africa. The main contributing factor to social stigma is that vitiligo is considered by many as wrath of the gods upon an individual, nemesis, a curse, mystery, spiritual attack etc. Further, because little or nothing had been heard about vitiligo in Africa before
now, people were left to make assumptions or create fantasies about the condition. It is shocking and alarming that till date some medical personnel believes and calls Vitiligo a spiritual issue.

As a result of the myths, some families especially in rural areas finds it difficult to educate their children with vitiligo (even when they want to, schools frowns at the kids joining the school) and tend to hide them as it is usually seen as shameful. Also, employers find it hard hiring individuals’ with vitiligo due to fears that their customers and staff will "catch" the condition, or that the customers would not want to continue patronizing them, so when they are considered, it’s usually for a position at the backend. See a video by VITSAF on this [http://youtu.be/LI9MA2Wefqo](http://youtu.be/LI9MA2Wefqo). Sadly, in some social settings, many individuals with Vitiligo are not offered the same kind of social & physical contact, due to this kind of misinformation.

Africa is highly religious and superstitious; the words of local prophets, native doctors (commonly called Dibia, Babalawo in Nigeria), uninformed herb sellers weigh heavily. For lack of patient care and attention to this condition in the Health sector most individuals have gone through so much pains, misinformation and harsh alternative treatment trials.

One particular tribe in Nigeria strongly believes that anyone who has vitiligo has offended the gods by eating a particular food forbidden by his/her family and that until the gods are appeased the vitiligo will not go away.

Another tribe believes that its thunder that urinated on the individual living with Vitiligo thus the ‘body peeling’ - depigmentation.
Another tribe believes that it’s a curse or nemesis: they practically see a person with vitiligo as someone who has committed an offence; the gods are visiting with vitiligo vengeance. In one of numerous instance I know of, a husband left his wife and kids because she suddenly started turning white, he believed it was nemesis from her family. To most especially women, marriage has become a distant dream. Women are fast becoming single parents in quest for love and belief that they will be married when pregnant. Even when two people agree to wed, the family imposes and cancels their nuptials (VITSAF has tried to address this issue in one of its videos linked http://youtu.be/yLTOcCqET00).

Vitiligo support groups across Africa shared the Beliefs and Powerful myths in their countries.

**In Uganda** a married woman was rejected by her husband because she developed vitiligo which became very severe on her face, and as a result the woman has confined to indoor existence. There are many people, in our country particularly in the village who are victims of VITILIGO whose family or relatives have rejected or ignored and denied them school. I will also never forget one person who mocked me and said I was a good sacrifice says Najukka Vivian, founder of Vitiligo Support in Uganda.

**In Ethiopia**, majority does not know what vitiligo is and its source. The society associates the cause of vitiligo to a curse, anger, sin, and punishment from God. Many people think and believe vitiligo is a curse, a punishment for eating something which is forbidden, deformity from the parents.

**Ghana**, Majority are not comfortable talking about their vitiligo for fear of rejection while many have also face severe rejection which has made them feel inferior and lack of self confidence in themselves. Many do not have access to the internet so they don’t know much about it, while some elderly
people have grown and accepted themselves just as they are, says Afezuke Gift, Ghana.

In South Africa no much research has been done Gaone Patronella says in her article ‘Myths about Vitiligo in S.A’, this evidence lies on old people that I have personally met in South Africa. I have undertaken a research on Vitiligo trying to get answers on the condition that has caused emotional stress and fear among individuals in the society. As I was growing being the only one with vitiligo I was scolded, isolated and tormented of my skin colour. It’s through such myths that the communities develop hatred and hostile feelings against individuals with vitiligo. Myths on vitiligo in SA:-

Mollo wa badimo - this is a Tswana saying which means you have been burnt by ancestral fires who are not happy about something, madi mabi- you have bad luck, I have a spiritual calling to be a Sangoma traditional healer.

In Kenya, They assume vitiligo to be wild things like, He must have crossed where the water used for bathing the twins was thrown, her grandparents are annoyed with her birth so the wrath of the ancestors are working on her, or it is a mystical factor “chira”. Others will talk about how one got burn with some hot water by the spouse shared James Laban, Founder of Vitiligo Society, Kenya.

Parents and elders have not helped matters. You see them warning their children and charges not to go near other children or people with vitiligo, as if it were contagious or a ‘curse’ might befall them. This video http://youtu.be/svYjaVMkHNw is based on one such true story:
Another parent shared how her daughter’s school called her to enquire about the white patches which had suddenly appeared on her daughter. Other parents were threatening to withdraw their children if her daughter was not removed from the school.

Unfortunately most individuals living with vitiligo in Africa believes in these myths making their cases more complicated and unhelpful. Surprisingly little is known about beliefs in relation to vitiligo.

Looking at it all, the primary Need and effective Solution to managing all these challenges to improve Quality of Life are Awareness, Enlightenment and Education. We need to get all of us structured on how best we can create and raise awareness while supporting and building confidence of individuals living with Vitiligo who look to us for succour in our individual communities. All our partner Vitiligo Support groups/organisation are independent.

We have launched our crowdfunding campaign to
● To raise funds for Vitiligo awareness, provide enlightenment and create extensive Vitiligo awareness/enlightenment and education through promotion, marketing and positive PR.

● To build capacity and structures and also inaugurate all partner groups of Vitiligo in Select Sub-Saharan Africa, where Vitiligo is still seen as being a curse, a frightening condition, nemesis, anger of the gods and a strange ailment.

● And to give seed funding and possibly stipends to coordinators/Executive Directors.

We also call for your partnership and support to any specific country in Sub-Saharan Africa of your choice, just let us know and we will link you up with them directly. If there is no Vitiligo support/organisation in your chosen country, we would be happy to initiate and inaugurate one with your help.

Thank you.