



KILISUN, SKIN CANCER PREVENTION FOR PERSONS WITH ALBINISM IN SUB-SAHARAN AFRICA

1. Albinism and skin cancer in Sub-Saharan Africa

A note about albinism

Albinism is a non-contagious congenital disorder characterized by the complete or partial absence of pigment in the skin, hair and eyes and affects people worldwide regardless of ethnicity or gender. The proportion of persons affected by albinism in the world varies by region. In Europe and North America, the frequency reported is 1 in 20,000. In **Sub-Saharan Africa** the **prevalence is much higher**, particular subgroups in southern Africa exhibiting prevalence rates of 1 in 1,000. In Tanzania the prevalence is estimated in 1 in 2,000.

Albinism in Africa: Myths and superstitions

Albinism is poorly understood in many African societies. Many Persons with Albinism (PWA) are stigmatized because of their appearance. Dehumanizing myths and superstitions surround the condition, with misconceptions leading to mockery, abandonment and violence. In Sub-Saharan Africa albinism is often understood to be a curse, or a contagious condition. Some believe PWA are not human and do not die, but are demons who disappear. The bodies of PWA are frequently said to possess magical properties, able to cure disease or deliver fortune; sex with a woman with albinism is thought to cure AIDS.

For all these reasons PWA in Africa face the threat of physical violence from infancy: in communities where dangerous myths are widespread, babies are routinely slaughtered at birth; those who survive endure years of abuse. Some are even targeted for their body parts, sold for thousands of dollars and used in witchcraft charms thought to bring fortune and wealth. This growing trade has led to the murder of 190 PWA in 27 African countries and 324 attacks including of mutilations, violence, rape, attempted abductions, missing, grave violations, asylum and permanent residency cases.



Tanzania presents a particularly severe case, with **77 PWA murdered** and 94 more attacked since 2006. Children are the target of the majority of violence incidents, roughly two-thirds of recorded murders are of children.

Albinism and Skin Cancer

Melanin is the natural photo-protectant that guards against the Ultraviolet damage in human skin. Owing to their lack of melanin PWA are particularly vulnerable to sun damage and prompt onset of skin cancer. Skin cancer in most of sub-Saharan African countries is a life-threatening condition and the leading cause of death for PWA. In Tanzania, where stigma is rife **only 10% of them live beyond the age of 30**. The World Health Organization recognizes albinism as a significant Public Health issue all over Africa and is currently investigating this at-risk population.



Evolution of skin solar damage in non sun-protected albino skin



Persons with albinism face multiple and intersecting forms of discrimination. As part of a vicious cycle of life after surviving at birth, they face constant threat of physical attacks. They are unlikely to get educated due to fear and lack of safety mechanism in schools. This lack of education leads to unemployment or menial **outdoor jobs, exposed to the sun** and increasing the risk of developing skin cancer.

Sun protection: the solution

Nonetheless, this **crisis is completely preventable**. With adequate sunscreen, wide-brimmed hats, long-sleeved clothing, sun protection education and regular medical check-ups, no person with albinism has to die of skin cancer. However, **sunscreen provision** is alarmingly **poor across Africa**. Associations of PWA of most Sub-saharan countries report that many health facilities do not have sunscreens, nor offer advice on UV radiation protection for PWA, nor albinism is included in health education programmes. There is no locally based production of sunscreens and these are imported or usually donated from abroad. Therefore the supply is sporadic and costly, with no structured distributional channels.

The amount of Ultraviolet radiation received in tropical latitudes is up to 200% the amount received in the North of Europe. Ensuring that PWA receive **high efficacy sunscreens** adapted to the environment and their extremely sensitive skins is essential.

Studies confirm that the most determinant factors affecting the **real effectiveness** of sunscreens are the **quantity** applied (71% impact) and the uniformity in the **application** (21% impact). Therefore, **education** on sunscreen use and follow-up **compliance** are as important as the provision of this lifesaving product.

2. Kilisun, special photo-protection to prevent skin cancer in Sub-Saharan Africa

Who we are

Kilimanjaro Suncare “**Kilisun**” is the **first sunscreen specially designed for the prevention of skin cancer in PWA in Sub-Saharan Africa**. The formulation has been carefully designed by first line cosmetic and chemical companies and adapted to the type of skin and reality of this vulnerable collective.

In 2012 the Spanish pharmacist Mafalda Soto pioneered Kilisun and launched the first production center, the **Kilimanjaro Sunscreen Production Unit**, at the Regional Dermatology Training Centre, dermatology department of the Kilimanjaro Christian Medical Centre, third referral hospital of Tanzania

Locally produced and distributed at no cost to its users, Kilisun has removed reliance on sporadic foreign donations, enabling a steady and sustainable supply of this life-saving product. Kilisun promotes local human resources, recruiting staff with albinism and facilitating albinism societies to co-lead distribution with in-country health and education professionals.



KSPU facilities



Kilisun production at the KSPU

The Kilimanjaro Sunscreen Production Unit (KSPU) manages the regular distribution of Kilisun to the most remote areas of Tanzania through mobile clinics, schools and other local platforms.

We emphasize the importance of sensitization and education on sun protection not only addressing the beneficiaries but their families and caretakers, dermatologists, teachers and the whole community. We ask the beneficiaries to return the empty containers with a quadruple goal: in order to assess and address compliance, for recycling purposes, to promote empowerment and for the creation of ownership among users.

The Kilisun package: A comprehensive approach

Kilisun is not a product but a holistic service. The **Kilisun package** comprises:

1. **Production** of a high protection sunscreen. Currently all the production takes place in the Kilimanjaro Sunscreen Production Unit, a specific laboratory that also employs PWA.



2. **Distribution** across all Tanzanian geography through dermatology consultants, community dermatologists, mobile clinics, schools, international NGOs and other local platforms.



3. **Education** on sun protection and albinism to PWA and families promoting **social inclusion**.



4. **Follow up** of the compliance and **measurement** of its **impact**.



Kilusun partners

Kilusun works in partnership with the **Minister of Health and Social Welfare of Tanzania**, **UNICEF Tanzania**, and the world-leading chemical company **BASF** (Germany). It also has the support of the **International League of Dermatology Societies** (UK) and the NGO **Africa Directo** (Spain).

The initiative has been presented in a great number of **international conferences** such as the XV World Congress of Cancers of the Skin (Edinburgh, 2014), the International Sun Protection Conference (London, 2015), the I Pan African Albinism Conference (Dar es Salaam, 2015) and the Action on Albinism Forum (Dar es Salaam, 2016).



Discussion panel at the "Action on Albinism in Africa" Forum

Kilisun impact

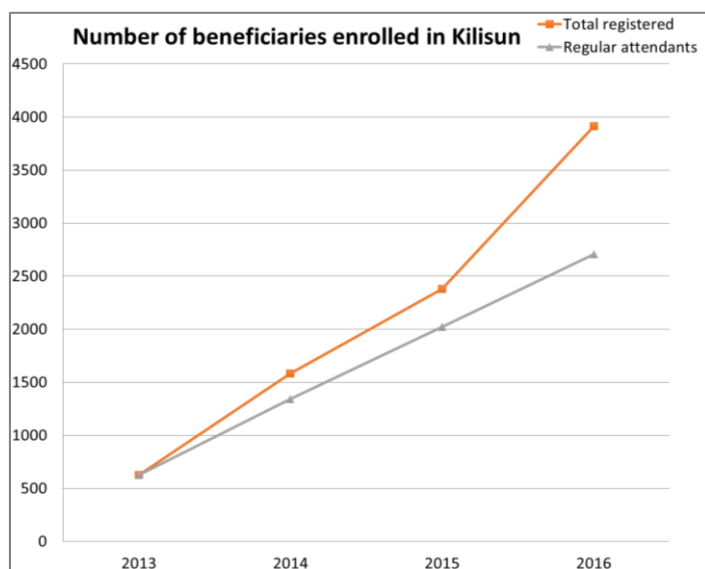
3,000 beneficiaries received Kilisun in 2016
51% of them are children
80% drop in skin cancer incidence

On January 2013 Kilisun was distributed for the first time to 25 children with albinism in a school of Kilimanjaro region, 4 years later **3000 persons are receiving Kilisun** on regular free basis along all Tanzanian geography.

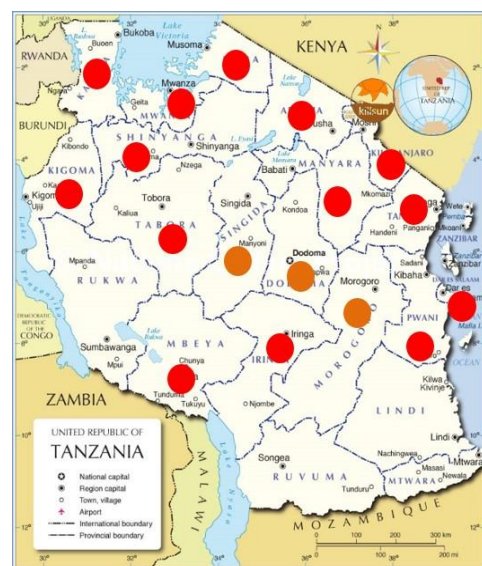
As indicated in the attached *2016 Activity Report*, more than **50% of the beneficiaries are children**, significant indicator as sun protection should start in very early stages of life.

The impact of the programme is clear: only 15 months of regular use of Kilisun services showed a **decrease in 80%** of both sunburn and **new skin cancer cases**.

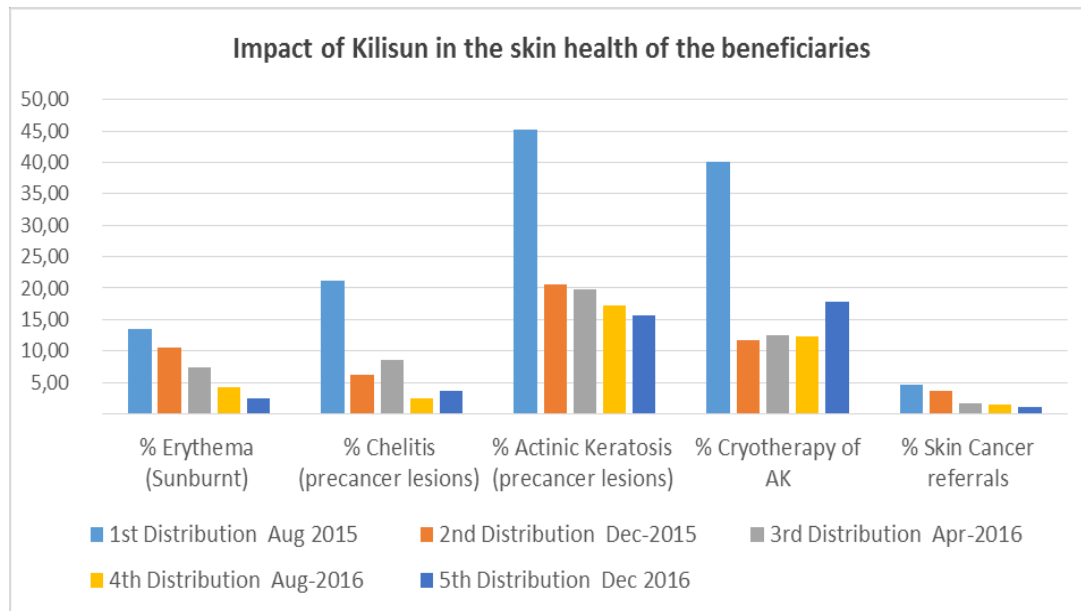
*More impact data and graphs in the enclosed *2016 Activity Report*.



Beneficiaries enrolled in Kilisun in Tanzania



Regions where Kilisun is distributed (red)
 New launching planned for 2017 (orange)



Decrease of the solar damage in the skin of PWA regularly receiving Kilisun services in 3 regions of Tanzania

We strongly believe that **regular provision of these services** across the country and the whole Sub-Saharan Africa will **dramatically reduce the morbi-mortality** of the disease, helping to win the battle against **skin cancer** among Persons with Albinism.

3. Expansion across Africa

Now that the model has been consolidated in Tanzania, Kilisun is working on the expansion and replication in other Sub-Saharan African countries.

We are specifically working on the expansion to Senegal and Malawi:

- **Malawi:** Kilisun is currently working with the *Association of People with Albinism in Malawi (APAM)*, United Nations and the Ministry of Health of Malawi in the details of an assessment trip that will take place in May 2017 to map the whole country, decide the site where to establish the production, design the distributions plan and finalize the budget. UN offices, the Ministry of Health and Pharmaceutical Services will co-fund the majority of the initiative. There are 8,000 Persons with Albinism living in Malawi.
- **Senegal:** we are working with the management of *L'Association Nationale des Albinos du Sénégal* to launch a local production unit replicating the Kilisun package, adapting it to the specific needs of Senegal. We have submitted a joint concept note to the Minister of Health of Senegal to explore the scope of their support. There are 10,000 Persons with Albinism living in this West African country.

4. Kilisun Care and Kilisun S.L.: Sustainability and innovation

A fast growth and an increasing impact have prompted Kilisun founder Mafalda Soto to **stablish the structure** that allows the initiative to **develop** and **expand** more **efficiently**. For that reason she moved back to Europe in 2016 and together with experts from the development and medical field she has developed two entities:

1. **Kilisun Care:** A **NGO** under registration in Spain that will be responsible of **managing the expansion** of Kilisun services in Africa, obtaining **resources** and establishing **partnerships** with key stakeholders to guarantee the smooth-running of all the operations in Africa.

Kilisun Care's launching is currently being supported by the *IE Business School of Madrid* and *the International Foundation of Dermatology* (London).

2. **KiliSun S.L.:** A **Social Enterprise** already registered in Spain that is developing a business model to ensure the financial independence, sustainability and scalability of Kilisun.

We always look into the sustainability and empowerment of local actors, for this reason our aim is that Kilisun S.L. establishes **public-private partnerships** with the **local Governments**. In Tanzania, the Ministry of Health is already supporting the production with human resources and tax exemption for the imported ingredients. In the countries where we are planning to expand our services it is a prerequisite that the local government contributes to the initiative co-funding the services, providing facilities, with human resources or covering the operations.



However, we are aware that not all the Governments of developing countries have budget to cover the costs to produce and distribute Kilisun; with Kilisun S.L. we also want to develop an **alternative source of revenue**: we are assessing the possibility of launching a social **sun care cosmetic line** in the European market, so that all the **benefits of the sales will be donated to Kilisun Care** NGO to cover the production and distribution **costs** of Kilisun **in Africa**. Kilisun S.L. is also the responsible organization of the **Research, Development and Innovation** activities.

Kilisun SL has received the [Gamechanger Award 2016](#) for social entrepreneurs in Health, being part of *Emprende in Health* programme supported by Unltd Spain and Laboratorios Lilly Spain. The **originality, innovation and scalability** of our initiative has inspired experts in the social entrepreneurship field. [Kilisun: protecting beyond the sun](#), business case is studied worldwide by leading Business Schools in emerging markets studies.



Kilisun S.L. founders with the rest of Emprende in Health winners

Conclusion

Both Kilisun SL and Kilisun Care exist to follow the original Kilisun goal of improving the quality of life of Persons with Albinism in Sub-Saharan Africa, ensuring that they have access to high quality sun protection through a quadruple intervention: locally **producing** a high efficacy sunscreen specially designed for their needs, **distributing** it free of cost to the users, providing **education** and **sensitization** to the users and their families and promoting their **insertion in society** through a **dignifying care** that help to raise their self-esteem and stand on their own.



Beneficiary 3 weeks before and after receiving Kilisun services

This two organizations work intensively to see a world where persons with albinism have equality of opportunities, health care access and life expectancy, enjoying the rights and freedom that enable them to stand on their own and be who they are.

5. Other relevant information

Press, media

<http://albinism.ohchr.org/story-mafalda-soto-valdes.html>

http://elpais.com/elpais/2014/12/01/planeta_futuro/1417455710_725799.html

<http://www.efesalud.com/noticias/crema-solar-para-albinos-en-africa/>

<http://www.agenciasinc.es/Reportajes/Fantasmas-quemados-por-el-sol>

<http://smoda.elpais.com/belleza/la-mujer-que-ama-a-los-albinos/>

<http://www.elmundo.es/yodona/lifestyle/2016/08/07/57a0800246163f95698b45dc.html>

<http://www.farodevigo.es/portada-ourense/2016/08/30/mafalda-soto-valdes-africanas/1523791.html>

Awards

2016 [Premio Gamechanger 2016](#)

2016 Premio de la American Academy of Dermatology

2015 Premio de la Fundación de la Academia Española de Dermatología y Venereología

2015 Premio de la American Academy of Dermatology

2012 Premio de la Fundación Cofares

Links

www.ponteensupiel.com

www.facebook.com/Kilisun