KILISUN:
Improving the quality of life of Persons with Albinism in Africa

MAFALDA SOTO VALDÉS
Co-Founder KiliSun
ALBINISM IN AFRICA

More than 200,000 persons have albinism
ALBINISM IN AFRICA: SOCIAL PROBLEMS

- Persons with Albinism (PWA) are victims of stigma and discrimination
- Only 10% have access to Secondary Education.
- 522 attacks to PWA have been reported in Sub-Saharan Africa since 2006. In Tanzania 77 have been killed and other 94 attacked.

“My teacher always said that when a person with albinism dies the body vanishes. So I was surprised that nothing happened here, we buried Mariam as any other person. Her body did not vanish, we did her a normal funeral”

Uncle of Mariam Emmanuel, murdered on January 21, 2008
TANZANIA

Tanzania occupies 151 of a total of 188 countries in the 2014 PNUD ranking (Human Development Index).

<table>
<thead>
<tr>
<th>SOCIOECONOMIC INDICATORS</th>
<th>TANZANIA</th>
<th>SPAIN</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surface (km²)</td>
<td>945.090</td>
<td>504.645</td>
</tr>
<tr>
<td>Maternity mortality rate (2010)</td>
<td>950</td>
<td>4</td>
</tr>
<tr>
<td>Doctors (for 100,000 inhabitants)</td>
<td>5</td>
<td>380</td>
</tr>
<tr>
<td>Malnutrition incidence (% total population)</td>
<td>38</td>
<td>...</td>
</tr>
<tr>
<td>Mortality index in under five children (for 10,000 born alive)</td>
<td>1.040</td>
<td>40</td>
</tr>
<tr>
<td>Population that lives with less than 1.25 USD/day (%) 2000-2008</td>
<td>88.5</td>
<td>0</td>
</tr>
</tbody>
</table>
ALBINISM IN AFRICA: ADVERSE EFFECTS OF SUN EXPOSURE IN THE SKIN

Their lifestyle, environment and social challenges make PWA specially vulnerable and exposed to sun damage.
ALBINISM IN AFRICA: ADVERSE EFFECTS OF SUN EXPOSURE IN THE SKIN

Only 1 out of 10 PWA live beyond 30 years
THE «SUN PROTECTION PACKAGE»

EDUCATION
Awareness, sensitization

- Sun safe practices
- Protective Gears
- Sunscreens
KILISUN

Adapted to THEIR reality and needs
SPF 30+, UVA/UVB coverage
Locally manufactured in own laboratory in Moshi (Tanzania)
Support of BASF Sun Care
The long way towards the ideal sunscreen—where we stand and what still needs to be done

Uli Osterwalder and Bernd Herzog

Received 30th November 2009, Accepted 4th December 2009
First published as an Advance Article on the web 1st March 2010
DOI: 10.1039/b9pp00178f

The magnitude and quality of UV protection provided by top considerably over the past three decades. As our knowledge a requirements increases, product and testing technologies adva technologies become available. The biannual London Sun Pr development over the last two decades. The 2009 edition of th: “Perfection of Protection”. This paper, based on our talk give question about the “ideal sunscreen” and explores four key re regarding where we stand on a ranking scale between poor an Technology is leading with a rating of 80%, Assessment/mea: Norms/standards around 50% and Compliance ranks only around 30% between poor and perfect. UV

Fig. 1 UV protection: four key requirements and influencing stakeholders.

Lack of Compliance = Problem #1
SPF IN VIVO VERITAS EFFICACY

- Spectral absorbance of product -SPF CLAIMED- IMPACT 8%
- Uniformity of application (Procedure) IMPACT 21%
- Quantity applied 2mg/cm² IMPACT 71%

B. Diffey, Photochem Photobiol, 2001, 74, 61-63
KILISUN: A COMPREHENSIVE PACKAGE

**DISTRIBUTION**

**EDUCATION**

**FOLLOW UP THE COMPLIANCE**

**IMPACT MEASUREMENT**
UNDERSTANDING SUNSCREEN LOTIONS AND ITS APPLICATIONS

RDTC at KCMC

KILIMANJARO SUNSCREEN PRODUCTION (KSPU)

• Produces and ensures free supply of sunscreens
• Promotes local human and material resources
• Does not rely on external donations of commercial products

KILIMANJARO SUNCARE (KILISUN)

• Sunscreen preferred by 67% of the study participants
• SPF 30+, UVA/UVB protection
• Specifically designed and formulated for PWAs of East Africa
**DISTRIBUTIONS IN 2016**

<table>
<thead>
<tr>
<th>Distribution channels</th>
<th>% Total beneficiaries</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outreach health programmes</td>
<td>75,44</td>
</tr>
<tr>
<td>Community Dermatologists</td>
<td>16,09</td>
</tr>
<tr>
<td>School and Centres</td>
<td>6,19</td>
</tr>
<tr>
<td>NGOs</td>
<td>2,28</td>
</tr>
</tbody>
</table>

**Average of return of containers in 2014:**

- **Highest in Kilimanjaro Region:** 63.73%
**KILISUN IMPACT**

3,000 beneficiaries received Kilisun in 2016

52% of them are children

80% drop in skin cancer incidence*

*After using the product*
KILISUN IMPACT

**Impact of Kilisun in the skin health of the beneficiaries**

<table>
<thead>
<tr>
<th>Region</th>
<th>Total Beneficiaries</th>
<th>Females</th>
<th>Children ≤18</th>
<th>Attended 2013</th>
<th>Attended 2014</th>
<th>% Receiving in 2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dar es Salaam</td>
<td>200</td>
<td>112</td>
<td>90</td>
<td>0</td>
<td>200</td>
<td>100%</td>
</tr>
<tr>
<td>Kilimanjaro</td>
<td>323</td>
<td>171</td>
<td>146</td>
<td>270</td>
<td>192</td>
<td>59.44%</td>
</tr>
<tr>
<td>Shinyanga</td>
<td>180</td>
<td>70</td>
<td>147</td>
<td>108</td>
<td>179</td>
<td>99.44%</td>
</tr>
<tr>
<td>Arusha</td>
<td>116</td>
<td>67</td>
<td>44</td>
<td>94</td>
<td>66</td>
<td>56.90%</td>
</tr>
<tr>
<td>Tanga</td>
<td>282</td>
<td>143</td>
<td>165</td>
<td>0</td>
<td>282</td>
<td>100%</td>
</tr>
<tr>
<td>Geita</td>
<td>85</td>
<td>45</td>
<td>46</td>
<td>0</td>
<td>85</td>
<td>100%</td>
</tr>
<tr>
<td>Mwanza</td>
<td>298</td>
<td>162</td>
<td>200</td>
<td>110</td>
<td>237</td>
<td>79.53%</td>
</tr>
<tr>
<td>Simiyu</td>
<td>42</td>
<td>25</td>
<td>41</td>
<td>0</td>
<td>42</td>
<td>100%</td>
</tr>
<tr>
<td>Mara</td>
<td>57</td>
<td>29</td>
<td>53</td>
<td>0</td>
<td>57</td>
<td>100%</td>
</tr>
<tr>
<td><strong>TOTALS</strong></td>
<td><strong>1,583</strong></td>
<td><strong>824</strong></td>
<td><strong>932</strong></td>
<td><strong>582</strong></td>
<td><strong>1,340</strong></td>
<td><strong>84.65%</strong></td>
</tr>
</tbody>
</table>

*Not beneficiaries of CCPPWA.*

Average of return of containers in 2014: 54,05% (Highest in Kilimanjaro Region 63,73%).

UNDERSTANDING SUNSCREEN LOTIONS AND ITS APPLICATIONS

RDTC at KCMC.
**COSTS OF THE PROGRAMME**

The annual cost of the Kilisun package in Tanzania is **50 Euro per person**.

<table>
<thead>
<tr>
<th>Region</th>
<th>Females 2013</th>
<th>Children ≤18 2013</th>
<th>Attended 2013</th>
<th>Attended 2014</th>
<th>% Receiving 2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dar es Salaam</td>
<td>200</td>
<td>112</td>
<td>90</td>
<td>0</td>
<td>100%</td>
</tr>
<tr>
<td>Kilimanjaro</td>
<td>323</td>
<td>171</td>
<td>146</td>
<td>270</td>
<td>59.44%</td>
</tr>
<tr>
<td>Shinyanga</td>
<td>180</td>
<td>70</td>
<td>147</td>
<td>108</td>
<td>99.44%</td>
</tr>
<tr>
<td>Arusha</td>
<td>116</td>
<td>67</td>
<td>44</td>
<td>94</td>
<td>56.90%</td>
</tr>
<tr>
<td>Tanga</td>
<td>282</td>
<td>143</td>
<td>165</td>
<td>0</td>
<td>100%</td>
</tr>
<tr>
<td>Geita</td>
<td>85</td>
<td>45</td>
<td>46</td>
<td>0</td>
<td>100%</td>
</tr>
<tr>
<td>Mwanza</td>
<td>298</td>
<td>162</td>
<td>200</td>
<td>110</td>
<td>79.53%</td>
</tr>
<tr>
<td>Simiyu</td>
<td>42</td>
<td>25</td>
<td>41</td>
<td>0</td>
<td>100%</td>
</tr>
<tr>
<td>Mara</td>
<td>57</td>
<td>29</td>
<td>53</td>
<td>0</td>
<td>100%</td>
</tr>
<tr>
<td>Iringa</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Not beneficiaries of CCPPWA.

Average of return of containers in 2014: 54,05,05 (Highest in Kilimanjaro Region 63,73,73).

The cost includes:

- Price of the cream (including the procurement of packaging, ingredients and production costs)
- Operational costs
- Distribution
- Educational programme
- Impact assessment and follow up of compliance
KILISUN CARE
N.G.O.

Mission: All Persons with Albinism have access to sunscreens

- Registered in Spain
- Ensures that PWA in Africa have access to sunscreen
- Manages the expansion of Kilisun services in Africa
- Obtains resources (funding)
- Establishes alliances with collaborators
- Ensures efficient operations in Africa
- Ensures sustainability of Kilisun in Africa:
  - Establishing Public Private Partnerships with Governments in Africa so the Government cover the costs of Kilisun (production, distribution, education, etc.) maximizing the impact at national level and making the programme sustainable
KILISUN CARE: THE EXPANSION

**Malawi:** Initial evaluation (May 17) with the Association of People with Albinism (APAM), United Nations and Ministry of Health.

**Objective:** Evaluate the situation in the country regarding sun protective services for PWA for a potential launching of Kilisun.

**Next step:** Presentation of findings and Intro proposal for pilot project in 2018 to MoH&UN (Oct. 17)

**Rwanda:** Piloting the launching of Kilisun in collaboration with HAND IN HAND FOR DEVELOPMENT (HIHD) and Ariana.

**Next step:** Training counterpart and launching of Kilisun services (March 2018)
ACHIEVEMENTS IN TANZANIA
- International visibility
- 3,000 PWA receive Kilisun sunscreen regularly
- (51% are children)
- 80% reduce skin cancer incidence
- We reach 21 of 25 regions in Tanzania

OUR VALUE
- Pioneers and unique
- Mission
- Social Impact
- Tested model in Tanzania ready to scale
- Trajectory
- Committed team
- International strategic collaborators
**KILISUN IN THE MEDIUM TERM**

- **Objective:** Reduce the morbi-mortality due to skin cancer among Persons with Albinism in Tanzania, Malawi and Rwanda

- **Implementation period:** January 2018 – December 2020

- **Expected results:**
  - **Consolidation** of Kilisun Care and Business model
  - **15,000 beneficiaries** receiving regular KiliSun services
  - Launching a **new SPF 50+ formulation** ("Kilisun Max" developed in partnership with BASF)
  - Launching an **impact study** and comparative study
  - Launching Kilisun in **two new countries**
Penye nia, pana njia
Where there is a wish, there is a will

Asanteni sana

mafalda.kilisun@gmail.com
www.kilisun.org