



## Comprehensive Care Programme for Persons with Albinism at the RDTC

JANUARY 2015 NEWSLETTER

It is our pleasure to introduce this first edition of the *RDTC Comprehensive Care Programme for Persons with Albinism in Tanzania (CCPPWA)* newsletter. We intend to make it a regular publication and to use it to keep you in touch with news and developments which relate to the services that the Regional Dermatology Training Centre at KCMC (RDTC) provides with the aim of improving the lives of Persons with Albinism (PWA) in Tanzania.

Nearly all PWA in East Africa will develop actinic keratosis before the age of 20, and their life expectancy is below 30 years. Similarly, a nearly 10,000-fold increase in skin cancer is reported in Persons with Xeroderma Pigmentosum (XP) under 20. The physical appearance, fear and superstitions surrounding PWA complicate their access to education, forcing them to work in outdoors settings. This contributes to a higher exposure of sun radiation that leads to No Melanoma Skin Cancers in very early life stages.

In 1993 the RDTC (Moshi, Tanzania) initiated an intervention programme focused on the prevention of skin cancers through early detection and treatment of its precursors. The CCPPWA has been assisting more than 800 PWA and 25 XP in Kilimanjaro and Arusha Regions through 8 stipulated Chapters: Skin care, eye care, educational support, general public awareness campaigns, initiation of indoor income-generating activities, participation in advocacy for PWA rights and equity, collaboration with other organizations and past-graduates of RDTC and conducting research activities.

### The Outreach services in 2014

400 beneficiaries were regularly visited in their communities in 2014. Provision of care services included registration, health education on sun protection, skin screening, treatment of premalignant skin cancers on the spot, referral for surgical removal of skin cancers and distribution of sun protective materials including hats, sun glasses and sunscreen. Education on life skills was also offered.

7 patients underwent specialized dermatologic cancer removal while 20 underwent eye assessment and provision of reading aids. More than 60 pupils benefited from educational support thanks to **Tumaini** (Austria).

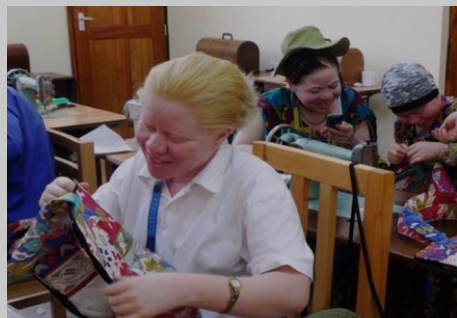


From 2013 the UK based charity **Standing Voice** supports the RDTC outreach expansion through the training and empowerment of community dermatologists working in the Lake Victoria and Northern Zone Regions. Hundreds of PWA are benefiting from an expansion aiming to reproduce the comprehensive outreach health care services across Tanzania.

CCPPWA takes advantage of special events to offer dermatological services. In May a team from the RDTC provided care for almost 300 PWA who attended The National Albino Day held at Dar-es-Salaam. This was preceded by an International Conference on Albinism that counted a symposia facilitated by 3 RDTC speakers.

## First Anniversary of the Care Unit for Persons with Albinism

On July the 24<sup>th</sup> the RDTC celebrated the first anniversary of the Grand Opening of the Care Unit of Persons with Albinism (CUPWA), a multipurpose building with two differentiated areas aiming to improve the quality of life of PWA.



The **Kilimanjaro Vocational Training Unit (KVTU)**, located in the CUPWA, was established with the aim of encouraging PWA to carry out indoor activities acquiring skills that help them to become self-sufficient. With the support of **Tumaini** (Austria) 10 women benefitted from a training on batik making in January. Recently transformed into the **Multiple Skills Training Workshop for Persons with disabling skin conditions (MSTW-PDSC)** the venue accommodated in November the 1<sup>st</sup> training on tailoring skills. It is expected that 20 workshops will be conducted annually.

## THE KILIMANJARO SUNSCREEN PRODUCTION UNIT



Established in 2013 with the support of **Under the Same Sun** (Canada), **Africa Directo** (Spain) and other stakeholders the **Kilimanjaro Sunscreen production Unit (KSPU)** is a RDTC based sunscreen factory. The initiative produces and ensures regular free supply of **Kilimanjaro Suncare sunscreen cream (KiliSun)** to 1,600 PWA across Tanzania, 60% of them are children.

The KSPU promotes local human and material resources focusing on the education of health personnel, beneficiaries, caretakers and teachers encouraging responsibility among the beneficiaries who should return the empty containers for recycling.

BASF, leader chemical company, provides free ingredients to the RDTC as well as scientific and regulatory background support for the development and manufacture of sunscreens for a period of 3 years.

The RDTC signed an agreement with UNICEF to jointly advocate with the Government of Tanzania to include the production and distribution of KiliSun under the Preventive Services of the Ministry of Health and Social Welfare by 2016.



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## RDTC in the World Congress of Cancers of the Skin

In September the **XV Congress of Cancers of the Skin** was hosted in Edinburgh. The reality of PWA in East Africa was present in two affiliated meetings. The KSPU and the development of KiliSun formula was present in a session prepared by **BASF**. The **IFD** organized a symposia on Skin Cancer in Resource-Poor Settings that counted with three speakers from Tanzania, Spain and the United Kingdom.



## Meet some of our staff



**Dr. Alfred Naburi** is the Manager of the CCPPWA since 2000. Trained at the RDTC and later graduated with a Master in Public Health at KCMUCo, he manages the implementation of the CCPPWA. He dreams to see the PWA in Tanzania free of skin cancer leading a self-sufficient life.



**Grace Yanyika** is the lab assistant and a pillar of the KSPU. Her two brothers with albinism died before turning 20. Her hard working and dedicated spirit is an inspiring example to other colleagues with albinism. Grace is mother of Meshack, an 8 year old boy.