



## UTSS ACTIVITIES

Link to UTSS: [www.underthesamesun.com](http://www.underthesamesun.com)

### ABBREVIATIONS:

**UTSS** = Under The Same Sun

**PWA** = Person(s) With Albinism

### NATIONAL ACTIVITIES:

**UTSS is involved with Advocacy & Education** at the grass roots level and all the way up to law makers in government and international powers like the UN & AU. We emphasize the scientific / medical Understanding of Albinism as a genetic condition, nothing more. We also emphasize social inclusion in all levels of society. People with albinism (PWA) are normal human beings just like everyone else. The problem is that “everyone else” is having a hard time accepting this reality. We dream of a day when people with albinism will take their rightful place in every level of society, EVERYWHERE.

**UTSS has put all of its eggs in the education basket.** Our **Advocacy and Public Awareness (APA)** program educates society about understanding and accepting albinism as a genetic condition, and our **Education Program (EP)** is offering academic and vocational education to Tanzanians with albinism. UTSS has placed, and is financially sponsoring, several hundred students with albinism into fully inclusive, high quality residential schools from kindergarten to graduate studies. With each year that passes there are more graduates with albinism entering the workforce in mainstream Tanzania society. These students and graduates are the strongest voice against discrimination and the most powerful message about the humanity, dignity and capability of persons with albinism. UTSS also has a fully inclusive Tanzanian office staff, 1/2 with albinism & half without, as a model of how to work and prosper TOGETHER within their own society.

### We also offer:

**Low Vision & Skin Care Clinics:** All PWA suffer with low vision. This must be assisted in order for them to function in academic, work and domestic environments and to alleviate the stigma that they are stupid and not worth educating, hiring or valuing. Also, in Tanzania, the number one killer of PWA is skin cancer. Less than 10% will live to age 30 and only 2% will live to celebrate their 40<sup>th</sup> birthday due to skin cancer. This is completely preventable! All students in our education program are offered Low Vision & Skin Care Clinics quarterly. This



service is now being provided to our students by a charity in Tanzania called Standing Voice who are assisted by UTSS during these clinics.

**Media Advocacy Campaigns:** Our Advocacy and Public Awareness (APA) program uses a variety of media to educate the Tanzanian public about albinism. To end myths and misinformation, we work tirelessly on developing proper publicity materials. These include brochures and leaflets that go into distribution through UTSS staff and our partners in the rural areas. APA also conducts specific programs to diffuse existing myths held within the country that lead to discrimination and justify the macabre killings. Media campaigns are ongoing and blitz the general public throughout the year with daily, weekly & monthly publications via TV, Radio, News Papers, Newsletters, Brochures & Magazine Publications.

**Understanding Albinism Seminars (UAS):** These 6 day tours, with 8 seminars in each, are offered once every 4 months, and more frequently if requested. A team of UTSS staff (both PWA & non-PWA) regularly offer UAS in various parts of Tanzania to educate their fellow citizens about the genetic condition of albinism by challenging myths with medically accurate information. This “in-person” encounter, where our PWA staff teaches their fellow citizens about albinism, helps humanize and personalize the issue and undermine discrimination. It is a highly interactive event with the audience where hearts and minds are enlightened and positive social change regularly takes place. We target both rural and urban centers including government agencies, hospitals, schools & universities, workplace environments, religious groups, police departments, villages, village elders, family members, etc.

**First Responder Team:** Within 24 to 72 hours after an attack against a PWA, UTSS sends a “First Responder Team” which attends the homes of victims and visits them in hospital if they are still healing. This is one of the unfortunate tasks we undertake which is an absolute necessity, since many victims of attacks are neglected by the government and their society. Since the investigative skills of police and journalist are frequently inadequate or simply absent, we visit victims, victim families and the affected community to record all relevant data related to the reported attack. We also spend considerable time and resources consoling and providing for the immediate needs of the traumatized family members as well as the victim (if he or she survived the attack). Most survivors will end up being enrolled in our education program were they will be safe and cared for. With each visit we take the opportunity to educate the families and community about albinism, offering genetic truths and dispelling traditional myths that spur attacks against PWA in the first place.

**Safe House:** Our safe house in Dar es Salaam is used to shelter PWA who have been attacked and whose families chose not to visit and support them since their attack. Most of these are children. Some also need to stay in the safe house when on vacation from school. Others will live their more permanently until they are able to fend for themselves. UTSS not only provides them with this shelter but also takes care of their educational and social needs.



**Psychological, Social and Medical Support:** People with albinism who have been directly attacked, as well as traumatized family members, are the beneficiaries of the UN Voluntary Fund for Victims of Torture (the UN Fund). The UN Fund has considered the type of attacks usually meted against PWA and the form in which it happened. This, together with the general impunity that often follows an attack, led the UN Fund to contribute support to these victims. The funds granted are administered entirely by UTSS and used to provide psychological and social support to all victims. This includes counselling from an experienced psychiatric nurse with albinism, and provision of basic needs including clothing and relocation allowance for movement to a safer place administered by our social welfare officer. These funds are also applied for those needing functional prosthetic limbs due to the loss of a limb in an attack.

**Summer Camps:** In July of 2013 and 2016 UTSS sponsored a week long camp for 170 children with albinism in Mwanza. This was bolstered by 40 volunteers from Tanzania, North American, South America and Europe. All of the kids were from our education program and have been abandoned by their families, leaving them with no place to go during their school summer vacation.

**Sunscreen Production:** UTSS has been a major financial sponsor of the local production of sunscreen in Tanzania. July 24, 2013, saw the grand opening of the Care Unit for Persons with Albinism (CUPWA) in Moshi, Tanzania. It is operated by the Regional Dermatology Training Center on the campus of Kilimanjaro Christian Medical Center. Thanks to the competent management of Mafalda Soto, a pharmacist from Spain, the facility is now fully functional and at the moment is able to supply 2000 PWA with sunscreen annually. We hope these numbers will increase and that in time the Tanzanian government will see this project as a model to be replicated in other locations throughout the country for their citizens with albinism. See video links for more information:

<https://www.youtube.com/watch?v=EfQGkPjjePc&feature=youtu.be>

<https://www.youtube.com/watch?v=Akli11QOV3w&list=UUR1PgNxAupmYjb48ATw-YQ>

**Collaborations with Local & International Diplomats in Tanzania:** The Canadian High Commission in Tanzania hosts regular events where UTSS is able to present an update on Albinism and Global Stigma to representatives from various diplomatic and international bodies from a diversity of regions and institutions including Africa, Europe, North America and the UN human rights office. This event has become a channel through which all these organizations can be updated from civil society and civil society in turn can consult attendees on strategies for enhancing collaboration with their respective offices as well Tanzanian national government. Their tangible support is demonstrated regularly. For example:

- An open letter was sent to the president of Tanzania, His Excellency Jakaya Mrisho Kikwete, expressing their collective concern regarding the safety and well-being of persons with albinism in the months leading up to Tanzania's national elections. It was



signed by Belgium, Canada, Denmark, EU, Finland, France, Germany, Ireland, Italy, Netherlands, Norway, Spain, Sweden, Switzerland, UK and USA.

- Only 2 weeks after the murder of a 40 year old woman with albinism, many of these diplomats formally requested justice in place of impunity at the office of Tanzania's Prime Minister.

**Archiving Research Findings on Albinism:** To improve our capacity as a research expert on albinism, we continually work on building and archiving all documentation we have collected to date including sound, print, visual materials, video footages, radio materials and news clips.

**Supporting International and Domestic Researchers and Media:** We give frequent support – human resources, attack documentation and other data related to albinism – to researchers and journalists investigating the plight of PWA across Tanzania, Africa and worldwide. We also attend and present at the largest conference on albinism, hosted in the USA by the National Organization for Albinism and Hypopigmentation (NOAH).

## **INTERNATIONAL ACTIVITIES:**

**Multiple Briefings of Treaty Bodies and Mechanisms at the UN:** UTSS has been the primary advisor to the UN in Geneva for 4 resolutions. The word “albino” or “person with albinism” did not exist in any UN Human Rights document until June 13, 2013, on which date the *first UN resolution* was passed decrying the human rights violations against PWA. Since then, a *second UN resolution* was passed requesting an Independent Expert be appointed to perform a global study about the human rights and wellbeing of PWA in all member states (countries belonging to the UN). A *third UN resolution* was adopted declaring International Albinism Awareness Day starting June 13, 2015 (the date of the first UN resolution representing the human rights of PWA globally). The *fourth resolution* was adopted on March 26, 2015. It is titled “Independent Expert on the Enjoyment of Human Rights of persons with albinism” and appoints an independent expert to investigate abuses suffered by persons with albinism worldwide. All 4 resolutions apply not only to Tanzania but to all PWA worldwide since discrimination against PWA is a global issue. You don't have to look past Hollywood productions and pop culture to see that PWA are not represented as normal human beings even in Canada, the USA and Europe.

**Multiple Briefings at the African Commission on Human and Peoples' Rights:** UTSS staff holds membership status and regularly attends and contributes at the human rights symposiums hosted by the African Union (AU) on the continent. On November 5, 2013, The African Commission on Human and Peoples' Rights, passed Resolution 263: On the Prevention of Attacks and Discrimination Against Persons with Albinism. The resolution was the first of its kind on the African continent and was very thorough.

**Pope Francis Meeting:** As part of his ongoing support on the issue of human rights of persons with albinism, Pope Francis granted UTSS' request to speak briefly with him (in the special



delegates section) after his weekly audience on Sept 10, 2014. He listened graciously, discussed and blessed our work.

**UTSS is involved in ongoing media spots** with outlets like BBC, Al Jazeera, AFP, Reuters and many more.

**Pan African Albinism Conference:** UTSS is sponsoring the first ever Pan-African Albinism Conference (PAAC) which will take place in Dar es Salaam, Tanzania, at the Julius Nyerere Conference Centre on November 19 – 22, 2015. We want this event to create a sanctuary of learning, networking and empowerment for PWA in Africa, equipping them with the best resources we have been able to accumulate to date. PWA representatives from over 25 African countries have registered for this event. There will also be guests in attendance from the UN, North America, Europe, New Zealand and Australia. The UTSS team is already very busy vetting applications, conference and lodging facilities, translation services and transportation. Note: the conference was originally scheduled for January 22-25, 2015, but had to be postponed to the above date due to the outbreak of the Ebola virus. UTSS hopes this will become the first of many such conferences on the continent of Africa.

Link to website: <http://www.underthesamesun.com/conference>

**International Albinism Awareness Day:** A Historic Global Celebration of Albinism - June 13, 2015, will see a worldwide celebration of the first UN sanctioned International Albinism Awareness Day (IAAD). UTSS will be celebrating this day in Tanzania, at the UN in Geneva and at the 25th World Congress of Dermatology in Vancouver.

Link to website: [www.albinismday.com](http://www.albinismday.com)

On November 18, 2014, due to advocacy by Under The Same Sun and cooperation with various UN bodies, (specific thanks to Ambassador Yusuf Mohamed Ismail Bari-Bari of Somalia and members of the Office of the High Commissioner for Human Rights) a third historic resolution on albinism was adopted by vote by the UN General Assembly in New York. In this resolution, the UN has declared June 13 as International Albinism Awareness Day (commencing 2015) which welcomes increased international attention, and recognizes the importance of increasing awareness and understanding of albinism in order to fight against global discrimination and stigma against persons with albinism.

**International Medical Relief:** In April of 2015, Elissa Montanti, Founder and Director of The Global Medical Relief Fund (GMRF [www.gmrchildren.org](http://www.gmrchildren.org)) in New York reached out to the children with albinism in Tanzania who had survived amputations due to machete attacks. In her initial email she said:

“I came across an article and learned about the horrific mutilation happening of children with albinism. It's just awful!! I'm looking for someone to help me make contact with the parents of children who are the victims of this atrocity. I can help with providing



prosthetic arms and legs. My partner in effort is the wonderful Shriners hospital for children. My charity provides the transportation, visa, room and board at no cost and the hospital, surgery (if needed) prosthetics and re-hab. The children we help stay in our program until 21, meaning we bring them back as they out grow their prosthetic and need a new fitting. I would love to help a child or as many as we could.”

In 2015 UTSS sent 6 children for new functional prosthetic arms. They are:

**Mwigulu Matonange** – 12 year old boy with albinism was attacked on 15 February, 2013. His left arm was chopped off above the elbow.

**Baraka Cosmas Rusambo** – 6 year old boy with albinism lost his right hand on March 07, 2015, in a witchcraft-related attack.

**Emmanuel Festo** – 16 year old boy with albinism who at age 7 survived a brutal machete attack on November 12, 2007. His left arm was hacked off above the elbow, the fingers of his right hand were chopped off.

**Pendo Sengerema** - 16 year old girl with albinism was attacked on August 5, 2014. Her right arm hacked off at the elbow.

**Kabula Nkalango** – 18 year old girl with albinism who survived a wicked machete attack on April 26, 2010, at the age 13. Her entire right arm was hacked off just below the shoulder.

**Kulwa Lusana** – 19 year old girl with albinism who survived a wicked machete attack on October 21, 2011, at the age 15. Her entire right arm was hacked off just above the elbow.

In 2017 four of these children returned to New York to have their functional prosthetic limbs refit and to receive follow up medical care. They are Mwigulu, Baraka, Emmanuel and Pendo. This is a service GMRF will continue until the age of 21.

### **UTSS Official Summary of Albinism:**

**Albinism is a rare, non-contagious, genetically inherited difference** occurring in both genders regardless of ethnicity, in all countries of the world. BOTH the father and mother must carry the gene for it to be passed on even if they do not have albinism themselves. The condition results in a lack of pigmentation in the hair, skin and eyes, causing vulnerability to sun exposure and bright light. Almost all people with albinism are visually impaired, with the majority being classified as “legally blind”. While numbers vary widely and no comprehensive studies have been conducted, it is reported that in North America and Europe, an estimate of 1 in every 17,000 to 20,000 people have albinism. In Africa it is estimated that 1 in every 5,000 to 15,000 people have





albinism with selected populations having estimates as high as 1 in 1,000. In Tanzania where UTSS is based, the prevalence of albinism is estimated to be 1 in 1,400 people being affected.

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