

Charity Description:

The Shade Tree Project (A Sombra da Arvore) was established in 2017 in response to the multiple needs of, and abuses against people with albinism (PWA) in Mozambique. PWA in Sub-Saharan Africa are dying at alarming rates mainly from skin cancer, but also from violence, mutilations, kidnappings and murders. We developed a multi-sectional dynamic approach with a diverse team of government agencies, and nonprofit and community organizations and members, to ensure long lasting and reaching effects of our programs to increase PWA life expectancy and quality of life, while building leaders for tomorrow.

Cancer Prevention: The Shade Tree Project developed a broad-spectrum 30 SPF natural sunscreen using fair-trade ingredients sustainably sourced in Africa. We hire and train PWA in Mozambique to produce the sunscreen providing a steady income for members of this chronically under-employed group. We, then, distribute the sunscreen, free-of-charge, as part of our comprehensive education and advocacy campaigns.

Our initial results have been overwhelmingly positive, with the vast majority claiming to use sunscreen on a regular basis and positive changes in many PWA's skin condition are visually apparent.

Education for PWA and their families: We travel to localities and districts throughout the province to hold community meetings and conduct in-home visits to effectually reach all members of the PWA population. During the community meetings, we invite the participation of district administrators, district directors of social services, members of the health and education departments, and community leaders creating a forum for open communication between the PWA community and the government and social leaders that can institutionalize change. We follow-up with visits to the individual homes of PWA to reinforce knowledge learned during the meetings, create a more in-depth discussion, and evaluate the impact of our programming. We also visit homes of individuals that did not attend the meetings to ensure the totality of the PWA population is reached.

During these visits, The Shade Tree Project leadership and our activists:

- explain the genetic cause of albinism and work to dispel the myths and misinformation of the condition;
- discuss threats of cancer caused by the sun and provide ways to protect themselves through clothing and sunscreen;
- distribute the sunscreen and demonstrate how to use it;
- encourage them to visit the doctor at least twice a year and advocate for their right to free health care, and to report it if they are denied;
- discuss how PWA can become more successful learners in school and encourage the families to advocate for better learning conditions and inclusion;

- talk about any prejudice or violence the PWA have confronted and give them resources and mechanisms for dealing with these situations, including reporting to the police, social services, or community leaders;
- encourage the PWA and their families to discuss albinism with other community members to help dispel myths and misinformation in their communities;
- share their own personal experiences to encourage an open dialogue.

We plan to visit our communities and homes every three months in hopes to establish a strong motivated informed PWA community. By facilitating conversations among PWA from different communities, we will make connections that can strengthen and empower the voices of PWA in Mozambique.

PWA advocacy in the schools: Most PWA have difficulties in school because of ocular problems, prejudice, and lack of knowledge of albinism. We developed an 8-page booklet, Guide for Teaching Students with Albinism, which explains albinism, identifies the special needs of students with albinism, and shows how teachers can help their students succeed and make an inclusive classroom and school by accommodating PWA special needs and fighting against prejudice. The Provincial Education Department will distribute the booklet to all schools and our PWA activists will visit the schools to lead a discussion about albinism, share their personal experiences, and encourage teachers and school staff to become advocates for change. The activists encourage local parents and PWA students to participate in the school presentations, empowering them to become self-advocates.

We have found that many families are keep the children with albinism, especially young girls, out of school for fear of violence, prejudice and/or ostracization. The Shade Tree Project will work with these families, the schools, and individual teachers to help assure a safe and positive learning environment for all students.

Activist Training: Activists for The Shade Tree Project serve as the cornerstone for creating an effective and vibrant movement towards institutional and social change in the lives of PWA. We train PWA, their friends and family to become advocates, educators and leaders in the community.

Our activist training workshops consists of targeted learning time, question and answer periods and role playing. The Provincial Director of Ophthalmology, the Provincial Director of Dermatology, Provincial Director of Education, and experienced activists and social workers participate in our meetings and provide the tools and knowledge for these future leaders. We will incorporate the prosecutor's office and self-defense techniques in the future workshops.

Our trained activists will work to:

- educate the PWA community and their families;

- advocate for PWA rights and inclusion in the schools;
- advocate for PWA rights at local health posts, clinics, and hospitals;
- and collect essential data to effectively build a movement and serve the PWA community.

Increasing access to healthcare: A surprising number of health professionals are mis-informed and/or under-informed about albinism, are unaware of PWA's right to free healthcare, and rarely discuss albinism with their PWA patients. PWA are mostly unaware of their right to free health care and generally do not go to the hospital to treat their skin or eye problems and if they do arrive for dermatological consults their cancers are in advance stages and are inoperable. Nampula does not have radiation or chemo therapies, therefore early cancer detection is essential in their long-term survival. Patients also complain of long waits or are not being seen on clinic days (there is only one dermatologist in the entire province) and lack of lenses that can help correct some vision problems.

We are working with the Nampula Provincial Hospital to ensure all PWA are given the free and adequate care. The dermatologist and ophthalmology department have committed to giving priority to PWA when they arrive at the hospital to reduce their wait times and to encourage return visits to the clinics. We are also working with the ophthalmology department to insure they have the proper lenses in-stock. Transport to and from the hospital is also a problem for PWA; we are working with the community to come up with creative solutions to resolve this issue. The Department of Health and The Shade Tree Project have initiated a bilingual (Portuguese and Macuua) radio campaign encouraging PWA to visit the dermatologist to combat cancer.

We will work with the district social services and health departments to insure their district and village clinics, health posts, and hospitals provide the free care to PWA, encourage clinical staff to talk to their patients about sun protection, to refer any patients with cancer to the central hospital, and refer PWA to The Shade Tree Project if they have not participated in our programming or been visited by our activists. After seeing the great health needs of PWA and with the Shade Tree Project's encouragement, the district social services and health department in one of our districts used their mobile clinic to provide "A Day of Albinism" where they provided basic primary care and screening for cancer in one of the district's remote localities with a high percentage of people with albinism. We will work to continually raise awareness of albinism in all of the communities and support and encourage government agencies to help meet the PWA needs.

We plan to write a guide to help health professional understand albinism and how they can make effective change in PWA lives. Our activists will present these guides to health

professionals, focusing on the health posts which generally only have health technicians working there.

Data Collection and PWA identification: There is little to no existing data on PWA in Mozambique and assumption for working with Mozambicans with albinism are based on regional trends and field observations. We are working with provincial, district and village leaders and community members to identify PWA. During our home visits, we collect basic demographic, socio-economic, and health information which can be entered into a disaggregated database. Our survey and one-on-one discussions will help us assess prior knowledge; family health history; greatest needs and barriers in terms of health, safety, and community acceptance; and what is needed to help improve PWA's lives. We document any skin problems such as burns, lesions, or cancer, as well as, any incidences of prejudice, threats, or violence.

On subsequent home visits, we assess the success and short-comings in our sunscreen and educational programs and document any changes within the household or the PWA lives.

This data will serve as a base knowledge and statistics to guide future health research or interventions. We will also generate reports of any significant findings to relevant health and human right groups and authorities.

Appeal: We are a young organization that has seen a multitude of positive results in our short time in action. We are working in partnership of many Mozambican government agencies, non-profit associations, and the PWA community to build comprehensive sustainable programs. We have yet to find a major funder and have been operating with the support of small grants and individual donations. Your support will make a real impact on the quality and longevity of PWA lives.