

## Kennington Overseas Aid 2017 Funding Proposal

### Standing Voice Vision Programme - Eye care clinics addressing the complex visual impairment of people with albinism

We respectfully request funding to the amount of £15,000 from Kennington Overseas Aid to support the development of Stage 2 of our Vision programme. KOA funding will support the delivery of large-scale vision clinics and the prescription of essential vision devices to ensure 1,150 people with albinism in Tanzania reach their educational and professional aspirations

#### About Standing Voice

Standing Voice is an international NGO based in Tanzania, with its headquarters in the United Kingdom. We exist to end human rights abuses against marginalised communities, and currently promote the social inclusion of people with albinism in Tanzania.

Albinism is a genetic condition that causes a melanin deficiency in the skin, eyes and hair. Globally 1 person in 18,000 has albinism. In Sub-Saharan Africa, however, the condition has a much higher prevalence: 1 in 1,400 are affected in parts of Tanzania, a frequency more than tenfold the global rate. In this region albinism is cloaked in ignorance and people with albinism rarely receive the rights and services they require. Often demonised as 'white ghosts' or supernatural curses, people with albinism are regularly denied access to healthcare, education, housing and employment. Babies are sometimes abandoned or killed at birth, and horrifyingly, hundreds of people with albinism across the continent have also been murdered for their body parts, used in witchcraft potions to bring wealth and fortune: in Tanzania, the epicentre of this crisis, 76 murders have been recorded since 2006.

Standing Voice has over 10 years of experience working with people with albinism, having been founded following the extraordinary global reaction to *In the Shadow of the Sun*, the 2012 BBC documentary film directed by Harry Freeland, our founder and CEO. Filmed over six years the film follows two men with albinism as they battled stigma to realise their hopes and dreams. It has now screened in cinemas and on television in 80 countries around the world (clip: <https://vimeo.com/51998785>). Today Standing Voice designs and delivers [Health](#) (Skin Cancer Prevention and Vision), [Education](#) (Scholarship support), [Advocacy](#) (Local, National, International initiatives) and [Community](#) (Tailored Support and Training) Programmes, reaching thousands of people with albinism across 29 African countries. These Programmes are blueprints: models to be adapted, upscaled and replicated internationally, wherever demand exists.

#### Albinism and Vision

People with albinism experience complex visual impairments. The melanin deficiency causes reduced pigmentation in the eye, increasing photosensitivity and impairing the ability of the iris to absorb light. As a result, people with albinism can experience discomfort in bright light. The front and back of the eye also develop differently due to the lack of melanin, altering the nerve connections between the eye and brain. This can lead to a number of eye conditions: Persons with albinism will typically lack precision or detail in their vision and many are classified as 'legally blind'; They are often affected by nystagmus, a condition causing involuntary, irregular eye movements; Some will also develop an eye turn or strabismus due to a failure of the optical pathways to develop in the same way. Consequentially, around 40% of children and 60% of adults with albinism require corrective glasses.



Optometry services, however, are extremely limited in Tanzania and East Africa. Without adequate care, these vision deficiencies affect education and employment levels of people with albinism. Only 10% of children with albinism in Tanzania have access to secondary education. Those lucky enough to attend school often struggle to read and need vision devices to participate in class. When these are not available, academic underperformance follows. Due to their poor education, people with albinism are then often unemployed and trapped in a structural cycle of poverty. Of those that do graduate, only 7% find formal employment. Others are forced to work in the sun as subsistence farmers, where they are at constant risk of contracting skin cancer.



### **Standing Voice Vision Programme: Stage 1**

Directed by world-leading optometrist and specialist in the low vision of people with albinism Dr Rebecca Kammer, Standing Voice's Vision Programme has activated and trained a network of local optometrists and wider community members to provide vision care and education to people with albinism in Tanzania since 2014. Our programme focuses on students with albinism in their formative years breaking the cycle of poor educational performance, unemployment, and further segregation.

We partner with the Kilimanjaro School of Optometry, the Tanzania Optometric Association, the Tanzanian Ministry of Health, local schools and private optics manufacturers to deliver vision care to people with albinism through low vision clinics. At each clinic every person with albinism receives a low vision examination and is prescribed vision devices suitable to their needs on site (monocular telescopes, handheld magnifiers, prescription glasses, UV-protective sunglasses). In addition education sessions and literature about low vision is provided. Improvements in patient vision is recorded through clinical data and we continually liaise with schools and study teacher feedback on the relevant child's performance, and compare his or her examination results before and after our services.

So far we have screened, examined and enrolled over 1,000 people with albinism on our Programme and distributed over 3,500 vision devices in total. Clinics operate in 11 locations across 6 regions of Tanzania.

## **Standing Voice Vision Programme: Stage 2 (Proposed)**

Standing Voice has been able to develop the second stage of its Vision Programme due to a three-year partnership with the Essilor Vision Foundation through its Vision For Life initiative. This will provide in-kind support for our new programme in the form of corrective lenses and sunglasses until the end of 2018 (£7,250 in 2017 with further support committed). We are now seeking further support to fund the three vision events and prescribe the in-kind donations.

Stage 2 has two planned core outputs: firstly, to deliver vision care and education to 1,150 people with albinism through 3 large 'Vision Events' over the course of 2017; secondly, to strengthen the welfare and performance of students with albinism specifically by providing specialist albinism training to create 'Vision Ambassadors' in the schools where we work.

### **Vision Events:**

These events—scheduled to take place in Bukoba, Dar es Salaam and Tanga, in the Spring, Summer and Autumn of 2017 respectively—will bring together hundreds of people with albinism to receive comprehensive vision care and health education en masse in one centralised location. By adopting this format, Standing Voice will be able to provide vision care to greater numbers in a shorter period of time and thus expand its reach. Our existing services will be provided through these events: low vision screening; distribution of vision devices including monocular telescopes; education about low vision and teacher training. Prescriptions will also be delivered on sight through a supply of pre-made glasses.

### **Vision Ambassador Training:**

Standing Voice will mobilise its existing network of schools and teachers to develop a structured support and monitoring system for the recipients of our vision events. Every school that participates in an event will nominate one of their teachers to undertake our Vision Ambassador Training Scheme. This nominee will receive formal training in basic optometry and inclusive teaching practices, as well as developing their understanding of albinism and monitoring and evaluation skills. Upon completion of this training, they will receive a certificate. Thereafter this Vision Ambassador will be an advocate for students with albinism in their school, providing continuous support for students with albinism as well as liaising with the Standing Voice Team to monitor students' progress and welfare.

By providing this training, our Vision Ambassador scheme will nurture a sense of ownership and responsibility among our partner schools and teachers. Not only will this empower them, providing them with new skills and an additional sense of purpose within their existing teacher roles, but it will also improve the efficiency and outreach of our existing programme. Rather than sending out optometrists at six month intervals to our partner schools, Standing Voice will be able to mobilise the Vision Ambassador network to provide care and support directly at the point of need in order to improve student health and welfare, combat bullying, and maximise academic performance. Ambassadors will also be able to provide more regular feedback on the progress of the students through a structured feedback system provided by Standing Voice. The creation of a Vision Ambassador Training Scheme is therefore critical to the long-term empowerment of children with albinism, delivering sustainable improvements to this population well beyond the immediate parameters of this project.

Watch the video of our latest Vision Event (<https://vimeo.com/164725523>) :



### Impact to date

The vision of our previous patients included within a recent study sample was recorded as 4.3 times better with the monocular telescope and 2.9 times better with prescription glasses on average. For children, receiving our service therefore improves their educational attainment and welfare in school, kick-starting a positive cycle that enhances their eligibility for higher education and training, and bolsters their future employability. For adults, vision care and education can dramatically transform their professional competency and socioeconomic security. The families and community members of our beneficiaries also benefit from these improvements in educational and professional prospects.

In addition, the experience of being examined is significant. Our previous patients report that through the examination they feel as if someone is taking the time to care for them. Many people with albinism have suffered severe trauma ranging from name-calling, bullying and abandonment by their family and community to, in some cases, violent physical abuse. Receiving the screening exam is an expression of care directed specifically towards people with albinism and is hugely valued by them. The vision care we will provide at our events could be a life transforming moment in enabling oneself to climb out of a life of severe discrimination and social exclusion.

### Budget

Item	Unit	Unit Cost (£)	Number	Total (£)
Venue hire and patient refreshments/meals	Per 5 day vision event	5,000	3	15,000
Transport for school pupils and teachers	Per 5 day vision event	1,500	3	4,500
Accommodation and subsistence for 5 optometrists	Per 5 day vision event	900	3	2,700
Media publicity for the event	Per 5 day vision event	500	3	1,500
Monocular telescope and other hand held magnifiers	Per magnifier	10	700	7,000
Cutting and edging prescription glasses	Per pair	3	610	1,830
Prescription lenses (in kind support)	Per pair	10	610	6,100
Sunglasses (in kind support)	Per pair	1	1,150	1,150
Education literature	Per leaflet	1	1,150	1,150
Contingency	Per 5 day vision event	200	3	600
<b>Project Total</b>				<b>41,530</b>

### Funds raised and sought

<b>Project Total</b>	<b>41,530</b>
Kennington Overseas Aid funding (sought)	15,000
In kind support (Essilor Vision for Life)	7,250
Secured funding in place	19,280