

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

Standing Voice received generous support from Kennington Overseas Aid towards the delivery of two core outputs between January and December 2017: firstly, providing vision care and education to 1,150 people with albinism through 3 large vision events; secondly, training a network of 30 'Vision Ambassadors' to support the welfare and performance of students with albinism in the schools where we work.

Outcomes

This project has had a huge organisational impact on Standing Voice. During 2016 we developed and refined our Vision Programme delivery model from more numerous but smaller clinics to large-scale events over consecutive days. This enabled us to provide care to more patients over a shorter period of time. In addition, our Vision Ambassador teacher training scheme was also introduced in 2016. Through the delivery of this project in 2017 our team have truly embedded these practices within programme delivery and have become exceptionally adept at delivering successful large-scale vision events and comprehensive teacher training thus increasing efficiency and effectiveness. This is a huge achievement for our nascent programme, which is the first of its kind in Sub-Saharan Africa.

The project has numerous key beneficiary groups:

- Patients benefitted from receiving comprehensive vision care and education which corrected their visual impairment through vision aids and training
- Teachers benefitted from receiving training in inclusive teaching practices further enabling additional benefits to students with albinism
- Optometrists benefitted by further developing their clinical skills in the low vision of people with albinism, which is poorly understood globally thus placing them at the forefront of delivering this unique rehabilitative care
- Government representatives (Social Welfare Officers and Special Education Officers) benefitted through programme engagement and formal training thus deepening their understanding of the visual impairment experienced by people with albinism and how to address it
- Wider community benefitted from exposure to this issue of visual impairment in people with albinism through national and local media

This project aimed to:

- 1) Provide access to specialists who can deliver low vision eye care services to 1,150 people with albinism
- 2) Train 30 Vision Ambassadors in schools to advocate for the needs and welfare of students with albinism
- 3) Continue to train 5 Tanzanian optometrists in low vision care for persons with albinism
- 4) Improve beneficiaries' vision and wellbeing through providing necessary aids

5) Educate beneficiaries on how to best manage individual vision needs

6) Educate wider community on complex visual impairment of people with albinism

Final project outcomes:

1) Across five vision events 1,204 patients with albinism received comprehensive vision care and were enrolled into the Standing Voice Vision Programme. We thus surpassed our patient target by an additional 54 patients and vision event target by two events. Clinic outputs detailed below.

	Total no. of patients	Total no. of students	Total no. of non-students	Total no. of glasses prescribed	No. of all glasses Dispensed on-site	No. of special order glasses	Total no. of sunglasses (prescribed and dispensed)	Total no. of monoculars (prescribed and dispensed)	Total no. of other magnifiers (prescribed and dispensed)
Geita Vision Event (March)	119	51	68	80	60	20	50	25	5
Dar es Salaam Vision Event (June)	465	249	216	249	206	43	413	216	59
Musoma Vision Event (September)	183	99	84	71	66	5	177	75	8
Mwanza Vision Event (November)	319	225	94	144	136	8	249	157	8
Bukoba Vision Event (December)	118	73	45	63	61	2	112	73	3
TOTALS	1,204	697	507	607	529	78	1,001	546	83

2) 63 teachers were trained as Vision Ambassadors in 2017, more than doubling our target of 30. We will monitor students academic attainment through the Vision Ambassadors trained. A sample of student beneficiaries from 2016 detailed a 5% improvement in examination scores. We anticipate similar outcomes from the programme in 2017 although this won't be revealed until the end of the academic year in 2018. Teachers routinely expresses their appreciation for the training they received which they reported as having a significant impact on their capacity to deliver inclusive teaching practices that incorporate the needs of students with albinism.

In addition to the teachers trained a further 5 Government Special Education Officers were similarly engaged. Special Education Officers are responsible for ensuring students with special educational needs receive adequate support in school. Many are ignorant of the special requirements of students with albinism. It is therefore vital that these key Government stakeholders are appropriately trained and are therefore better equipped to support teachers within their catchments. In addition to the formal training provided to Special Education Officers numerous Social Welfare

Officers supported with ensuring patient attendance through accompanying them to the clinic. Deepening relations between Social Welfare Officers and patients with albinism is a further outcome of this project.

3) 5 optometrists from three health facilities (KCMC School of Optometry – Moshi, Temeke Hospital – Dar es Salaam, Mt Meru Hospital – Arusha) delivered vision events this year continuing their clinical development. Standing Voice Vision Programme Director Dr Rebecca Kammer was in attendance during the Dar es Salaam Vision Event to provide further on the job training and mentoring.

4) A total of 607 pairs of prescription glasses, 1001 pairs of sunglasses, 546 monoculars and 83 other magnifiers were prescribed and dispensed to patients. Analysis of clinical data from a sample of 71 patients that received both prescription glasses and a monocular revealed considerable improvement in visual acuity with the vision devices prescribed.

	Mean Acuity Result		Improvement in Vision
	Ratio	Decimal	
Uncorrected Visual Acuity	2/20	0.11	n/a
Corrected Visual Acuity (w glasses)	2/12	0.16	1.45 times better
Corrected Visual Acuity (w monocular)	2/4	0.47	4.27 times better

In addition to improvements in vision, many patients reported improvements in comfort and confidence as a result of receiving comprehensive eye care from the Vision Programme. Below is a patient testimony revealing the positive impact of the support received on general wellbeing, and economic empowerment in this instance.

I am a tailor, my job needs me to have good vision otherwise I won't get it right. I am 50 yrs old and have been doing this job for about 30 years. My vision, although not excellent, has been adequate but it is getting even worse as my age goes, the older I grow the poorer the vision I experience. I had started losing hope with my vision, but Standing Voice has brought my hopes back. Look at these glasses, they are my new eyes.

David Paschal, 50 yrs, Kagera Region

5) At each vision event patients received a comprehensive eye examination during which optometrists explained to them the nature of their visual impairment, the devices that they prescribed to assist them and how to use those devices. In addition each student that was prescribed a monocular telescope received an additional training session, delivered by Standing Voice staff, to further assist with how to use the monocular and to enable them to practice with it.

6) Concerted efforts were made to engage national and local media in the Vision Programme this year with the aim of increasing awareness of the visual impairment experienced by people with albinism. In Tanzania coverage was generally in the form of TV News pieces during which all programme funders were thanked. Media outlets in attendance in 2017: ITV, Azam TV, Clouds Media Group, Star TV, Channel Ten TV, TBC. In addition SV produced two social media stories on vision events this year that can be accessed via the links below:

<https://standingvoice.exposure.co/vision-clinic>

<https://standingvoice.exposure.co/vision-clinic-1>

Project Expenditure

Item	Original Budget (£)	Actual Expenditure (£)
Venue hire and patient refreshments/meals	15,000	5,389.99
Transport for patients and teachers	4,500	2,606.01
Optometrists Accommodation and subsistence	2,700	2,704.33
Media publicity	1,500	1,239.25
Monocular telescopes and other vision devices	7,000	11,377.01
Cutting and edging prescription glasses	1,830	792.02
Prescription lenses (in kind support)	6,100	6,100 (received in-kind)
Sunglasses (in kind support)	1,150	1,150 (received in-kind)
Education literature	1,150	283.63
Contingency	600	445.64
Clinic delivery team transport	-	4,136.40
SV staff accommodation and subsistence	-	2,766.42
Vision Ambassador accommodation and subsistence	-	1,460.94
Coordination support from partners	-	1,324.63
TOTAL	41,530	41,776.27

During 2017 we were fortunate to benefit from increased Government engagement in the Vision Programme. With regards to budgetary implications this manifested itself in the provision of free vision event venue space in certain clinic locations. We were therefore able to reallocate funds assigned to this budget line to other expenses that were due to come from Standing Voice's reserves.

Future Plans

In 2018 we aim to increase the intensity of Vision Programme activity with seven vision events scheduled aiming to reach over 1,800 patients by the end of the year. In addition we intend to increase the number of Tanzanian Optometrists supporting the programme and have a training event planned in February. We have invited 8 new Optometrists to this event alongside the 5 we currently work with. Our Vision Programme Director Dr Rebecca Kammer is flying over from the US to deliver this training.

We have also secured funding to recruit a Vision Ambassador Support Officer who's sole focus will be to ensure the teachers we have trained fulfil their role as advocates for inclusive teaching in their schools. Our ultimate aim from the Vision Ambassador Training Scheme is for all supported students with albinism to realise their educational potential. We believe the recruitment of the Vision Ambassador Support Officer will hugely contribute to achieving this.

