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Standing Voice is an international NGO promoting the social inclusion and wellbeing of people with albinism.

Last month Standing Voice coordinated a 3-day event delivering low vision care and education to 302 patients with albinism from across the Lake Zone of Tanzania. Held on March 13-15 at Malaika Beach Resort in Mwanza City, this event launched a three-year partnership between Standing Voice and Vision For Life, a charitable initiative created by Essilor. Service delivery was led by Standing Voice Vision Programme Director Dr Rebecca Kammer and our team of in-country optometrists. Here we encapsulate the event, extending sincere thanks, and the invitation of future collaboration, to all key partners and stakeholders involved.

CONTEXT

People with albinism have a melanin deficiency that reduces pigmentation in the skin, eyes and hair. This creates a complex visual impairment, altering retinal development and nerve connections to the eye.

Optometry services are extremely limited in Tanzania, so the unique vision needs of people with albinism are often overlooked. This has serious consequences for educational participation and performance. If fortunate enough to secure secondary education, most children with albinism will be unable to read from standard distances. Ensuing struggles with academic performance further ingrain stigma, and contribute to common perceptions that children with albinism do not belong in schools. Many students leave school ostracised and unskilled, facing a future of unemployment.

Standing Voice's Vision Programme was established in early 2014 to remedy this situation. The programme is a network of clinics, delivering low vision care and devices to people with albinism across 7 regions of Tanzania.

Clinics provide every student with a low vision examination, a monocular telescope, a pair of UV-protective sunglasses, and an educational session and booklet about low vision. Approximately 40% of all persons with albinism require prescription glasses, with our in-country optometrists prescribing these on site. We also aim to deepen teachers' understanding of albinism, equipping them with the knowledge required to improve student care and combat bullying. We educate teachers about the implications of albinism on vision in the classroom, and how the condition might affect social interactions between children in and out of class.

To date, the programme has served over 800 students through low vision intervention and healthcare education. Over time we aim to capture the impact of this service on students' pursuit of higher education and employment.

We collect comprehensive patient data, including devices distributed and prescriptions issued. This enables us not only to track patient progress but also to accurately forecast how many pairs of prescription glasses are likely to be needed for a given cohort of students. By creating an inventory of specialised glasses to be issued on-site, we save both money and time: patients receive the vision devices they need with minimal waste and delay.

As part of our Vision Programme, this event sought to address the following problems:

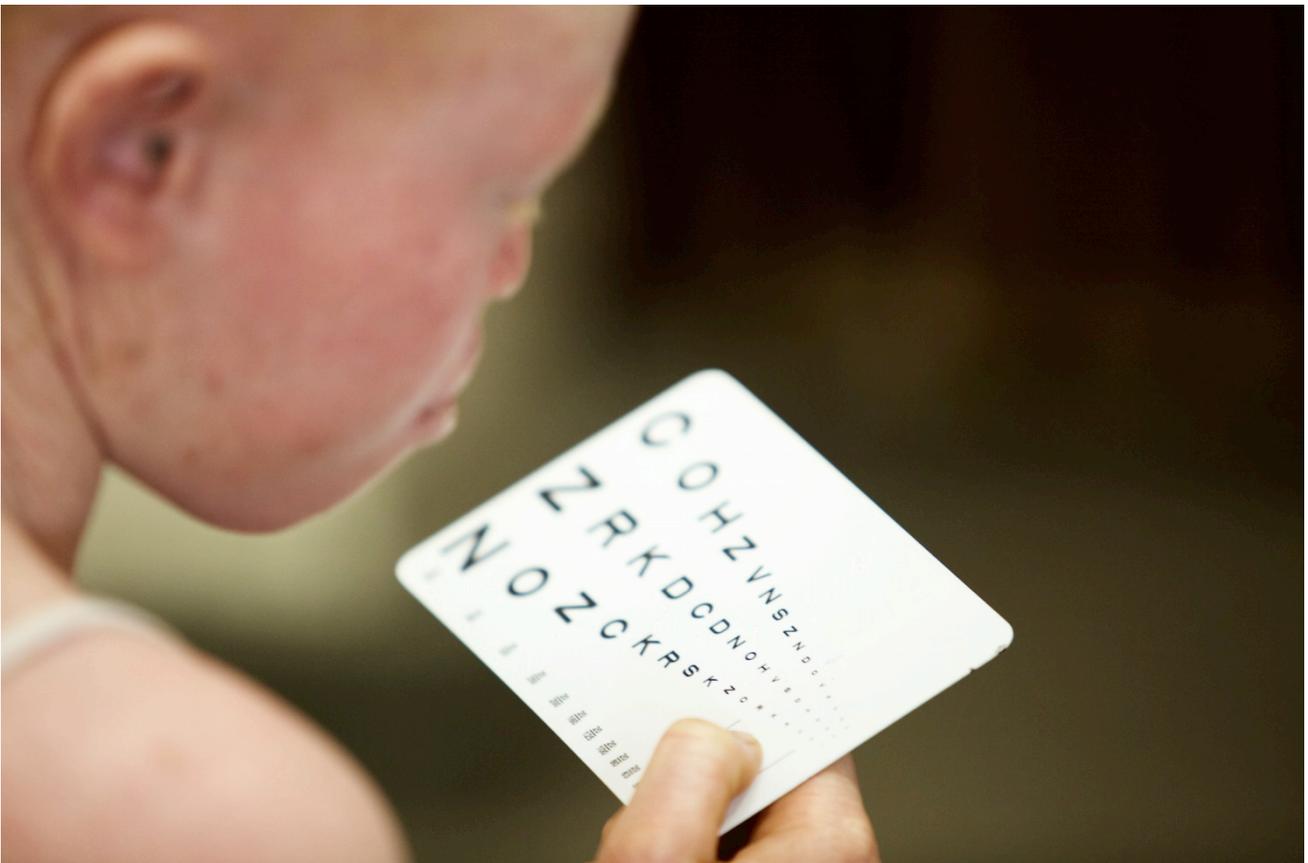
1. Lack of vision devices to help students with albinism learn in school
2. Lack of education for students with albinism about their visual impairment and how it can be managed
3. Lack of education for teachers of students with albinism about low vision care
4. Lack of structured optometry services and training in Tanzania
5. Lack of statistical data and research on the low vision of persons with albinism in Tanzania
6. Disconnect between students with albinism and stakeholders able to directly enhance their wellbeing

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EVENT

The event marked the formal commencement of Standing Voice's three-year partnership with Vision For Life, a strategic giving fund created by Essilor, the world's leading lens producer and a specialist in ophthalmic optics. Vision For Life has pledged thousands of corrective lenses and sunglasses in support of our Vision Programme. These will equip Standing Voice to expand its current service, more than quadrupling its reach. With Vision For Life's support we will improve educational opportunities and visual health for children with albinism by providing examinations, magnifiers, education, and sunglasses to 4,200 students. Of these, an estimated 1,800 will also receive corrective lenses, the majority of which are photochromic, darkening when exposed to sunlight to protect eyes against sun damage.



All photographs by Ezekiel Mkusa / UTSS

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KEY PARTNERS AND PARTICIPANTS

Vision For Life (Essilor)

Our Vision Programme's main partner, Vision For Life donated hundreds of vision devices to this event and made indispensable contributions to service delivery and press conference discussion. We were honoured to be joined by Aïcha Mokdahi, Vision For Life's Executive Director; Olivier Martin, Essilor International's East Africa Business Development Director; Laurent Dosseville, Director of Commercial Sales, EMEA at Transitions Optical; and Marie-Caroline Robin, an apprentice at Essilor

Under The Same Sun (UTSS)

A key NGO partner of Standing Voice, UTSS facilitated the attendance of 150 of its grantees as recipients of our service, coordinating transport for these students and also helping to organise video coverage of the event; we were delighted to receive the support of UTSS staff members Grace Wabanhu, Raymond Muganyizi, and Ezekiel Mkusa

Tanzania Albinism Society (TAS)

A civil society organisation whose broad membership base is vital for connecting us to beneficiaries; we were grateful to receive the support of Mwanza Albinism Society members Alfred Kapole, Angelina Chuma, and Saimon Chasama for the duration of the event

New Light Children Center Organisation (NELICO)

Another NGO partner, NELICO facilitated the transport of students to our event

Kilimanjaro Christian Medical Centre (KCMC) School of Optometry

Key in-country optometry training facility whose network of professionals is crucial to our service delivery; several of Standing Voice's programme optometrists were recruited through KCMC

The Tanzania Optometric Association (TOA)

A professional optometry organisation whose network of in-country optometrists has proven invaluable to Standing Voice in the delivery of our Vision Programme



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SPECIAL GUESTS

Hon. Dr. Abdallah Possi MP (Guest of Honour)

As the first Deputy Minister with albinism in Tanzania (Deputy State Minister in the Prime Minister's Office responsible for Policy, Parliamentary Affairs, Labour, Employment, Youth and the Disabled), Dr Possi received a full tour of the service, attended a senior meeting, and played a critical role in shaping press conference discussion; his attendance signals increasing government involvement in the improvement of healthcare and other services for Tanzanians with albinism

Aïcha Mokdahi

Ms Mokdahi is the Executive Director of Vision For Life; together with Standing Voice CEO and Founder Harry Freeland she launched the event and formally inaugurated the three-year partnership between Standing Voice and Vision For Life; she also hosted guests, spoke before national and regional media, and contributed to press conference discussion

Nemes Temba

As the newly appointed Chair of TAS and representative of all albinism society branches nationwide, Mr Temba received a formal tour of our services and also took part as a patient

Alfred Kapole

As Chair of the Mwanza Albinism Society, Mr Kapole was instrumental in coordinating the attendance of many beneficiaries from the Mwanza region; he met with our optometrists, participated in a press conference and senior meeting, and, like Mr Temba, received a full tour of the services and also participated as a patient

Manju Salim Msambya

As the Acting Mwanza Regional Commissioner, Mr Msambya participated in our press conference and spoke on behalf of the regional government

Augustine Senga

As the Mwanza Regional Crimes Officer, Mr Senga was a key participant in the press conference, speaking about law enforcement authorities' efforts to prevent violence against people with albinism; he also provided free security for this event

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BENEFICIARIES

Of the 302 patients who attended this event, 275 were students from 23 educational institutions:

| | |
|---|----|
| Shinyanga Secondary School | 24 |
| Dekapoli School | 27 |
| Mingas School | 25 |
| Under Lake School | 3 |
| Lakeview School | 56 |
| Mitindo School | 19 |
| Geita Secondary | 4 |
| Lweno School (Geita) | 1 |
| Kishirina School (Geita) | 1 |
| Nayankumu School (Geita) | 1 |
| Kanyara School (Geita) | 1 |
| Mkolani School | 17 |
| Alliance Primary School | 7 |
| Alliance Secondary School | 33 |
| Buhangija School | 44 |
| Kom School (Buhangija) | 2 |
| St Augustine University (Mwanza Community) | 1 |
| Gedeli Primary School (Mwanza Community) | 1 |
| KKKT IMAN Nursery School (Mwanza Community) | 1 |
| Mwambani School (Mwanza Community) | 1 |
| Ibeshi School (Mwanza Community) | 1 |
| Busara School (Mwanza Community) | 1 |
| Hisani School (Mwanza Community) | 4 |

The additional 27 patients were invited community members from Standing Voice project sites who we felt would benefit from our vision service:

| | |
|---------------------|----|
| Mwanza Community | 18 |
| Ukerewe Community | 6 |
| Shinyanga Community | 1 |
| Others | 2 |

Of the 275 students listed above, 150 were UTSS grantees:

| | |
|--|----|
| Mingas School | 23 |
| Under Lake School | 3 |
| Busara English Medium School | 1 |
| St Augustine University | 2 |
| Loreto Girls Secondary School | 1 |
| University of Dar es Salaam: Computing Center, Mwanza branch | 1 |
| Dekapoli School | 27 |
| Alliance School | 39 |
| Lake View School | 53 |



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PRESS

Union of Tanzania Press Clubs (UTPC)

A key partner of Standing Voice and vital press organisation committed to promoting socially progressive causes in national media, the UTPC publicised our event, ensuring a high and diverse turnout for the press conference

Mwanza Youth Network (MYN)

A youth media institution committed to positive and progressive coverage of this issue, the MYN attended our press conference to produce radio material; by engaging with the MYN Standing Voice seeks to nurture interest in social justice and ethical journalism among the next generation of Tanzanian society

Other key outlets in attendance

Newspapers

- The Guardian
- Nipashe
- Uhuru
- Daily News
- Tanzania Daima
- Mtanzania
- Mwananchi

Television Networks

- ITV
- TBC
- STAR TV



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INDICATORS OF SUCCESS

In light of the problems this event sought to address, we identified the following key successes:

1. Lack of vision devices to help students with albinism learn in school
 - ✓ Of 302 patients, 296 received sunglasses and 254 received monocular telescopes. 37% required prescription glasses, with 113 pairs prescribed and given on site and a further 14 prescribed to be ordered. 5 additional magnifiers were given on site.
2. Lack of education for students with albinism about their visual impairment and how it can be managed
 - ✓ Of 302 patients, 301 received on-site education about low vision care. 1 student with special educational needs could not participate, but will receive the necessary education through his teacher at a later date.
3. Lack of education for teachers of students with albinism about low vision care
 - ✓ Teaching representatives from 15 educational institutions attended and all participated in workshops designed to deepen their understanding of albinism and low vision and therefore build their capacity to support the educational development of students with albinism.
4. Lack of structured optometry services and training in Tanzania
 - ✓ Our growing team of in-country optometrists continued to develop its expertise in the field. Trained by Dr. Kammer, our team is broadening access to vision care and education for people with albinism in Tanzania. Our programme expands training to reach more dermatologists, mobilising the workforce in a targeted way.
5. Lack of statistical data and research on the low vision of persons with albinism in Tanzania
 - ✓ Dr. Kammer and our team of optometrists continued to collect data on the vision needs of students with albinism in Tanzania. Their research is at the cutting edge of this field and yields new insights, which help improve quality of (and access to) care. For example, Dr. Kammer's estimate that 40% of students would require prescription glasses—a figure calculated from prior clinical research—was accurately reflected in this event, and enabled us to plan for that number of prescriptions in an efficient and cost-effective way.
6. Disconnect between students with albinism and stakeholders able to directly enhance their wellbeing
 - ✓ By connecting students with albinism to local and national government, civil society organisations and progressive media institutions, we are forging links between our beneficiaries and broader society. This propels the situation of people with albinism to the front of the national agenda in Tanzania and creates an attitude of collective responsibility around the welfare, prosperity and security of this group.

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CHALLENGES

⇒ Non-typical programme delivery

- Historically the Vision Programme has operated through a dispersed network of clinics inside schools. To formally celebrate the partnership with Vision For Life, this event instead brought hundreds of children with albinism to one centralised location in Mwanza, where they all received our care en masse. Adopting non-typical clinical delivery in this way—serving greater numbers in a compressed period of time—intensified logistical demands. Due to effective planning, and excellent management by Event Coordinator Jayne Waitheera, we were fortunate to encounter no major obstacles.

⇒ Retention of devices

- Some students had previously received vision devices prior to this event. In a number of cases, these devices had been lost or damaged. To maximise retention of the devices we prescribed, we spoke to each beneficiary individually (and in our programme education sessions) to discuss measures for improving storage and care of these devices. Parents and teachers, who provide critical oversight in the use of vision devices, were also involved in such discussions.

⇒ Waiting times

- Students who had travelled greater distances to attend the Vision Event were given priority in the queue. Some local schools unfortunately endured longer waiting times as a result. We mitigated this by providing children with lunch and refreshments, balloons, and access to an outdoor playground.

⇒ On-site prescriptions

- Our on-site delivery of pre-made prescription glasses was a huge success, with 113 pairs prescribed on site. However, due to the complexity of some prescriptions, 14 beneficiaries were unable to receive glasses during the event. These have to be produced off-site and delivered to students in their schools.



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FUTURE RECOMMENDATIONS

⇒ **Family and community**

- Parents should encourage greater care in the storage and use of vision devices: left unsupervised, many young students break or lose their vision devices; alongside teachers, parents share the responsibility of ensuring children understand how to protect and maintain these devices
- Parents should spend time understanding their children's vision needs and managing these needs at home
- Parents should ensure children are encouraged to excel and achieve, and are brought up with a belief in their own abilities unhindered by their visual impairment

⇒ **Civil society (CSOs, NGOs, press organisations)**

- We invite civil society actors to work closely with Standing Voice, to inform us of areas with large numbers of children with albinism without low vision support, and where possible to connect us to these beneficiaries

⇒ **Government**

- Greater resources allocated to the promotion of albinism awareness in government schools and teacher training colleges
- Greater resources allocated to optometry services for people with albinism in Tanzania
- Greater effort on behalf of the government to monitor and evaluate rates of enrolment and performance among students with albinism across Tanzania

⇒ **Health providers and professionals**

- Optometrists in Tanzania are encouraged to connect with our Vision Programme and join our expanding network of in-country optometrists
- Optometry training centres should incorporate modules on the unique vision impairment associated with albinism into their curricula, thereby increasing understanding in the field of optometry more broadly

⇒ **Education providers and professionals**

- Teachers and matrons have a significant responsibility to ensure greater care in the storage and use of vision devices, particularly for younger students; teachers share this responsibility with students themselves, as well as their parents and families
- Teachers should implement the learning they have gained from Standing Voice about how to meet the unique vision needs of students with albinism: checking that devices are properly used and maintained; ensuring each child is sat comfortably and in the right position; ensuring other children understand the vision needs of their peers with albinism, and how to manage these needs

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LOOKING AHEAD

From inception to delivery this event involved an array of in-country stakeholders: like all our programme clinics, it was organised in collaboration with our wonderful partners, publicised before media and government, and delivered by our team of Tanzanian optometrists and facilitators. This event marked the beginning of a long-term relationship with Vision For Life, whose pledge of vision devices and corrective lenses to our Vision Programme will ensure thousands of children with albinism receive the tools they need to succeed in school in the coming years.

Through this event the Vision Programme is continuing to spark a national conversation around visual health and educational opportunities for children with albinism and create a collaborative arena in which a variety of stakeholders can work to support this vulnerable group. Teachers, matrons, facilitators, NGOs, press, government and civil society: together we are stitching the fabric of sustainable vision care for thousands of people with albinism, whose futures are brighter because of this service.



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THANKS

Heartfelt thanks to our Vision Programme partners Vision For Life, UTSS, TAS, NELICO, KCMC School of Optometry and TOA. Thanks to Hon. Dr. Abdallah Possi MP, our Guest of Honour, and to the Government of Tanzania more broadly; and to our other esteemed guests Aicha Mokdahi, Nemes Temba, Alfred Kapole, Manju Salim Msambya, Augustine Senga, Olivier Martin, Laurent Dosseville, and Marie-Caroline Robin.

Thanks also to UTPC, MYN, and other media outlets who attended; and to Malaika Beach Resort for providing free venue space. Thanks to the wonderful Standing Voice team, including Dr Rebecca Kammer and our four Tanzanian optometrists: Dr Focus P. Maro, Dr Kanuti Siara, Dr Abdi K. Nyembo, and Dr Sospeter Wilson Ntoke. Thanks lastly to the teachers and parents who attended this event, and to the students with albinism without whom this service would not exist.



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